



Simon, Oliver, Edward, and Vilma at Edward's graduation from St. Stephen's Episcopal Day School, Miami, a few days before Oliver suffered the onset of headaches and two weeks before he died.

HOW LOSING A SON INSPIRED AN EFFORT TO FIGHT PEDIATRIC CANCER

BY SIMON STRONG '77

We were supposed to be at Lake Tahoe, after a glorious spring term when our younger son had graduated from our beloved Miami elementary school, and his brother, Oliver, had finished a jubilant first year as a middle-schooler, discovered his love and talent for the saxophone, and been re-selected as goalkeeper for a top Florida soccer team. Instead, one week after the onset of headaches that had curtailed Oliver's tennis camp, and 36 hours after he had been diagnosed with acute myeloid leukemia, my wife Vilma and I were in a hospital room about 20 meters away from where, at dawn on June 18, 2015, he had just passed away on a trolley. Through a fog of utterly indescribable torment we begged his oncologist for answers. "What caused this?" we asked. Amid her own tears, she replied: "It's the environment." And so our odyssey began.

FOR DECADES I HAVE WORKED

as a reporter, author, and corporate investigator, researching and writing for some of the highest-profile media and publishing houses in the English-speaking world, and more recently for some of the best-known investigative companies.

In the weeks following Oliver's death, as I groped for meaning and truth, I learned for the first time that cancer was overwhelmingly triggered by environmental factors — even if the actual mechanisms were deeply complex and barely understood.

That first revelation was best crystallized in a World Health Organization (WHO) paper I stumbled upon. Subsequently, I found it in the work of UC Berkeley's professor of toxicology, Dr. Martyn Smith (now on our scientific advisory panel), focusing on the key characteristics of carcinogens, also published by the WHO. It confounded my own prior assumptions as well as those of most of my friends and acquaintances.

To the extent I had ever thought about cancer at all — like many of us outside the healthcare profession, I preferred to avoid dwelling on illness — I had always seen the disease broadly as a matter of bad luck and, to use a very British adjective, dodgy genes.

The revelation that cancer was environmentally driven was empowering, if enraging. It meant that, at least in theory, cancer was a preventable disease. And that if we as a species ceased to poison our planet — global warming being just one consequence of human pollution — we could cease to poison ourselves.

Yet it took time for my appreciation of the integral, and at some level ineffable, relationship between human beings and our physical environment to take center stage.

That should perhaps not have been the case. At Hotchkiss, as an English-Speaking Union exchange student arriving in senior year, I was privileged to take a nature writing course with Blair Torrey, during which we studied Annie Dillard's *Pilgrim at Tinker Creek* and spent many an hour penning our observations and reflections in the School's magical woods.

I should have dug deeper and searched out Dillard's literary and spiritual

progenitor, Henry Thoreau, not just another transcendentalist but a far more acerbic critic of environmental pollution and degradation. That would come later (and Ralph Waldo Emerson, too).

Still, a seed was sown. And there was a through-line. As part of our contemplation of nature, we did spend precious time at Succor Brook. Years later, on a sweet June afternoon, Oliver and his younger brother, Edward, laughed and splashed beside its rocks during our Class of 1977's 35th reunion weekend.

With savage synchronicity, in writing this article I realize the class reunion fell on the same month and day that Oliver spent his final night at Miami Children's Hospital, three years later.

My second revelation in the weeks that followed our son's death was that the pediatric cancer rate has soared nearly 50% since 1975. It is the leading cause of death in children and teenagers, other than accidents. Bafflingly, the data starting at me from the Centers for Disease Control and Prevention (CDC) website had attracted not a single media mention. One pediatric oncologist even denied it was true, until I showed him the data. Why had it increased so much?

At the same time, wherever I looked,

I was being reassured about the five-year survival rate, averaging 80%. Less commonly reported was a study in the *Journal of the American Medical Association* finding that more than 95% of childhood cancer survivors had a chronic health condition by the age of 45 — because of the cancer itself, or more commonly, its treatment.

Seeking to explore how I could drive awareness as well as research into prevention — instead of focusing on detection, diagnosis and treatment, like other charities — I turned to a statistics professor in Florida who had authored papers on pediatric cancer clusters. A few phone calls later, an excited cancer epidemiologist at Harvard Medical School connected me to Baylor College of Medicine in Houston, ironically the beating heart of the global oil industry driving most of our pollution.

For several years Baylor, part of Texas Children's Hospital, the nation's largest pediatric cancer center, had been administering an epidemiological questionnaire to in-patients, focusing primarily on lifestyle and genetic factors. Baylor's Professor Michael Scheurer, director of the Childhood Cancer Epidemiology and Prevention Program, was excited to launch a web-based study to reach a wider



Oliver's friends and family in Miami at a "Light the Night" rally of the Leukemia and Lymphoma Society.

range and a much larger number of families — volume being critical to identifying meaningful environmental associations — on a shorter timeline.

And together with input from a former CDC toxicologist, Dr. David Brown, whom I had encountered because of his work on the health impacts of fracking as well as the carcinogenicity of the dioxin-up, used vehicle tires deployed on artificial sports fields, we developed a questionnaire that interrogated broader environmental exposures.

Our role in the study, named TheReasonsWhyUs, is to recruit its participants. They sign up at our website of the same name. We transfer their basic data to Dr. Scheurer's team, who follow up with the online questionnaire. This bifurcated approach enables us to focus freely on communication and community outreach and Baylor to focus solely on the study itself.

We launched TheReasonsWhyUs in 2020. It comprises a family questionnaire covering diet, neonatal practices, medications, and infections, as well as sports, leisure, and other personal and consumer activities. Once the data is collected, Dr. Scheurer's team will assess exposures to key toxicants. That will involve multiple datasets including air and water studies, exposure to pollution, and the collection and analysis of baby teeth — which record when certain toxicants, including metals and pesticides, penetrate our bodies.

As a result of our expanding grassroots community outreach and some key media coverage (*The Guardian, Environmental Health News*), so far around 600 families have signed up from 46 states, as well as from several other countries. Modest this might seem, but by comparison the hugely ambitious National Children's Study tragically collapsed in 2014 after spending \$1.2 billion and managing to recruit just 5,000 pregnant mothers.

To be successful, to find the answers our families seek, and for Baylor's study to yield the evidence we all need to identify and to control the toxicants imperiling our children's health (the pediatric incidence of most other non-infectious illnesses and conditions has also surged), it is critical we drive our numbers into the many thousands.

Dr. Philip Landrigan, a legendary pediatrician, thanks to whose crusading efforts lead was removed from gasoline and

who is professor of biology and director, Global Observatory on Pollution and Health, Boston College, has joined our scientific advisory panel. He says: "We must support strong research programs like this that include epidemiological and toxicological studies. Very large participation is crucial to obtain the data we need to design evidence-based programs for disease prevention in children. Research into cancer prevention must be funded on at least an equal level with research into cancer treatment. We must strengthen state and federal laws to better protect our children — and we must enforce those laws.

"Pediatric cancer is the canary in the coal mine for human health. Health effects may be gross and obvious, such as cancer or death, or they may be subtle, such as delays in development or impairment of immune function. There are more than 85,000 manufactured chemicals in use in America today. Only a handful have been tested for safety or toxicity. Children are more vulnerable because of their greater environmental exposure pound for pound than adults, coupled with the exquisite vulnerability that is a consequence of the rapid and incredibly complex growth and development of their organ systems. And the physiological effects are cumulative and long-term."

The scale of our ambition for TheReasonsWhyUs, the key project of our non-profit The Oliver Foundation, sometimes overwhelms. But we are garnering the support of the world's most eminent pediatric and cancer scientists, including Dr. Margaret Kripke, former chief academic officer at University of Texas MD Anderson Cancer Center. Dr. Kripke served multiple terms on the three-person President's Cancer Panel, where she produced the groundbreaking 2009 report, *Reducing Environmental Cancer Risk: What We Can Do Now*.

At the same time, we are no longer quite so alone in our prevention-focused, paradigm-shifting mission. In 2020, even as the first of our families began to take the questionnaire, more than 60 groups focused on environmental health, and comprising scientists, business leaders and policy experts, formed the Childhood Cancer Prevention Initiative. This led to a report

(*Childhood Cancer: Cross-Sector Strategies for Prevention*) calling for "chemical producers, manufacturers, and retailers to turn off the tap on toxic chemicals and replace them with viable, safer alternatives that people can access regardless of their economic status."

And we have demonstrated proof of concept. Splitting the recruitment of families affected by pediatric cancer from the execution of the study itself has opened the doors to the volume and diversity of data critical to the study's success. And Dr. Scheurer describes the response rate by our families upon Baylor's outreach to them as "unprecedented."

Yet, reaching the Hispanic and African-American communities who suffer the brunt of environmental injustice is a major challenge. With regard to the Hispanic community, my Colombian wife Vilma's role as a reporter for Univision, the biggest Spanish-language news network, is a godsend.

Our key objective is recruitment — for which we are looking to design and execute a comprehensive and inclusive communications strategy that inspires and embraces affected families across the USA and across the world who seek not only answers, but also change.

Our participating families are extraordinarily brave. Some have lost their children: some are supporting them during the anguish, and financial uncertainty, of treatment; and some are blessed to have children in full remission. What we all have in common is the hope our contribution will lead, one day, toward a cleaner world in which we humans prove ourselves more worthy stewards of our planet — and are blessed in turn with healthier lives.

As a family, Vilma, Edward, and I feel blessed that Oliver — a deeply empathic and compassionate boy already passionate about social injustice — has gifted us this chance to serve. 🙏

Simon Strong is CEO of Tendacis International, a business intelligence and corporate investigations firm. He lives in Miami, FL, with his wife, Vilma, and son, Edward. He also serves as executive director of The Oliver Foundation, www.therasonswhyus.org. Brett Pierce, class of '77, who was Oliver's godfather, also serves on the Foundation's board.