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TRUST FOR AMERICA'S HEALTH



year
in
review

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MISSION

Trust for America's Health is a national non-profit organization whose mission is to protect the health and safety of all communities, especially those most at risk of environmental and other public health threats. Our goal is to strengthen the nation's public health system through science-based research, community partnerships, education, and advocacy.

FROM THE EXECUTIVE DIRECTOR



Like so many around the country and the world, we were shocked and saddened by the events of September 11, 2001. The terrorist attacks and anthrax mailings have forever changed our nation.

Prior to the attacks, the American public had little notion of public health. In contrast, when it comes to health, several nationwide polls have shown that there is great concern across the country. The public is worried about rising rates of asthma, childhood cancer, developmental disabilities and auto-immune diseases—many of which may be related to our environment. All of them may be preventable.

But our public health system, which is designed to protect us from multiple health risks, is under-prepared and too-long neglected for the job. Trust for America's Health (TFAH) was launched in February 2001 to be the voice for rebuilding our public health defenses against environmental risks—whether accidental, chronic, or deliberate acts of terrorism.

In our first year, we have successfully led the call for improving the nation's public health by making our voice heard through national and regional news stories, publicly released science-based reports, briefings to state and national policymakers, meetings with community activists, our interactive website, and our daily work with environmental health groups.

TFAH's first campaign has been a huge success, with Congress approving appropriations of almost \$30 million in fiscal year 2002 to begin a nationwide health tracking network. Surveillance, or tracking and monitoring, of diseases is the foundation of public health and dates back more than a century in our nation's history. However, our nation currently has no comprehensive network to track chronic diseases, even though they account for 70 percent of the annual deaths in this country.

Tracking where and when chronic diseases such as asthma and cancer occur and their potential relationship to environmental factors is key to helping public health officials implement better prevention strategies. Now that Congress has made a down payment on a nationwide tracking network, TFAH will continue to urge additional funding to build the capacity of state and local health departments.

The terrorist attacks have revealed what many in public health have known for years—state and national resources for public health preparedness are woefully inadequate. TFAH has called for strengthening public health through early warning and communications networks, more and better-trained public health officials, more laboratory capacity and tracking of diseases and environmental exposures.

Investing in these fundamentals of public health will also help prepare us for the risks posed by hazardous chemicals stored and transported in thousands of communities across the nation, substances that could be used in potential terrorist acts. To defend the American people from multiple health threats, our public health system needs the capacity and resources to respond rapidly.

TFAH's work on these issues is just the beginning of our long-term commitment as a public health advocacy organization. We understand that public health is more than a one-shot deal; it's an ongoing challenge to ensure healthier people. We look forward to working with you in the year ahead.

Shelley A. Hearne, DrPH





“the U.S. public health infrastructure, which protects the Nation against the spread of disease and environmental and occupational hazards, is still structurally weak in nearly every area.”

From the Centers for Disease Control and Prevention’s (CDC) 2001 report, “Public Health’s Infrastructure.”



PUBLIC HEALTH ON THE FRONT LINES OF DEFENSE

September 11 has refocused the public and policymakers on the importance of public health. As important as police and fire protection, public health is on the front lines of our defense. Its success begins at the local level and requires a coordinated effort among local, state and federal public health agencies.

The nuts-and-bolts for preventing disease and improving health—the public health infrastructure—include trained professional staff, disease tracking, information and communication systems, and strong health departments and laboratories. But after decades of federal, state and local neglect, there are gaps in this front-line defense for protecting our nation.

Today, too many communities don't have all the resources they need to protect their health. Working with other health and environmental groups, TFAH is advocating for increased investment in our public health infrastructure. America's public

health system is vital to our defense against biological and chemical attacks, as well as serious chronic health concerns such as asthma, birth defects and cancer.

TFAH's staff have briefed reporters and editorial board writers on the need for strengthening public health's infrastructure, and participated in a panel discussion with U.S. Senator Bill Frist (R-TN) and Dr. Anthony Fauci from the National Institute of Allergies and Infectious Diseases on National Public Radio's "Diane Rehm Show."

In letters to U.S. Health and Human Services Secretary Tommy Thompson and to U.S. Senators and Representatives, as well as an op-ed written for Former Secretary of Health and Human Services Donna Shalala, TFAH has called for greater support for public health fundamentals.

As Americans become increasingly concerned with our ability to contend with an attack involving chemical or biological agents, as the recent cases of anthrax show, we should consider the implications of this scenario:

In a community, doctors notice an influx of patients complaining of headaches, nausea and dizziness. First it's diagnosed as a flu outbreak, but as patients deteriorate, doctors suspect something else.

Patient symptoms are linked to exposure to a nerve-gas-type agent. Alarmed officials consider evacuating thousands of residents. Soon, public-health professionals enter the scene. They determine who is most at risk, clearing the way for a targeted, rational response that prioritizes treatment, calms fears, avoids broad panic, saves millions of dollars in unnecessary expenditures and, most important, saves lives.

This is a true story. It happened in Jackson County, Miss., in 1996. There, more than 1,000 people were exposed to a chemical that had been illegally sprayed by pest exterminators.

What does this event tell us about America's ability to deal with a chemical or biological assault? That our public-health and medical professionals are in critical need of the training, resources and communications networks that will allow them to quickly detect and respond to chemical or biological threats to public health.

The bad news from Jackson County is that doctors were slow to recognize what was wrong with their patients while the initial response from authorities leaned heavily toward a massive evacuation that was not warranted. The good news is that no one died. In addition, public-health advocates have been learning lessons from this episode long before the Sept. 11 attacks and the ensuing debate about our preparedness for chemical or biological terror.

This analysis also has been a broader probing of the gaps in our public-health infrastructure that impede our ability to respond to perilous health events. These include exposures to hazardous toxins, whether introduced by terrorists or by a sloppy exterminator, and the sudden spread of a potentially lethal infectious disease, be it through the malicious release of genetically modified smallpox by a rogue state, or a spontaneous eruption of dengue fever.

Once loosed upon the population, any exposure or outbreak becomes a public-health event. Even if the specter of chemical and biological terrorism did not loom large, our growing knowledge about the relationship between environmental exposures and human health justifies the action that the federal government is contemplating in the name of national security.

In a report released last year, the Pew Environmental Health Commission said that the situation in Jackson County demonstrates the need for a much-improved national public-health network. It notes that communication and information flow among medical and public-health professionals at local, state and national levels need to become matters of routine, rather than ad hoc interactions that occur only in a crisis.

National health experts have long agreed that America needs to strengthen its public-health defenses. Rising to the challenges of our time requires smart investments in an infrastructure that enables hospitals, public-health laboratories, medical professionals and public-health experts to constantly monitor our exposures to toxins and infections and that trains them how to respond in concert when threats emerge.

Investing in this infrastructure would help us prepare for a crisis and respond to public-health needs that have been neglected for far too long. We possess the know-how and plans to bolster our defenses. The only thing lacking has been the political will to act.

That appears to have changed. The renewed focus on public health since Sept. 11 has all the makings of a sentinel event for our public-health system. The important thing now is to take the necessary actions to protect public health. Health security is as basic a right of Americans as police and fire protection. And in times of crisis such as this, it is clear to all that health security is synonymous with national security.

Donna E. Shalala, president of the University of Miami, was secretary for Health and Human Services from 1993 to 2001.

EXCERPT FROM TFAH OCTOBER 2001 LETTER
TO HHS SECRETARY TOMMY THOMPSON

“Mr. Secretary, as you know, public health protection is as essential to our quality of life as police and fire protection... We hope you will give equal priority to both chemical and biological risks, including those posed by toxic substances already present in our communities; and that you will support the call for a more fully developed national ‘early warning’ and health-tracking system to handle both chronic and acute health crises.”



In advertisements running in *The New York Times*, *The Wall Street Journal* and *The Washington Post*, TFAH joined with several national public health and medical organizations to call on Congress to strengthen the nation's public health system by investing in the fundamentals of public health. The American Medical Association, the National Association of County and City Health Officials, and the American Public Health Association were among the groups endorsing the ad.



It's Time to Strengthen Our Front Lines in the Fight Against Bioterrorism

We have learned the critical role of public health in recent events. But today, in many of our communities... the front lines in the fight against bioterrorism... aren't there when we need them most to protect our people.

Changes in how we live, the best way to help some and save others... the stability and resilience of our public health systems, including "early warning" and communication systems, more training for professionals, better equipped public health laboratories, and tracking of diseases.

Investments like these would improve our capacity at the local, state and federal levels to respond to both biological threats and everyday health concerns like asthma, food safety, birth defects, and cancer.

A 30-person group of 2007-2008 U.S. Senators asked to send to Congress a resolution that "There is the time to strengthen our public health system."

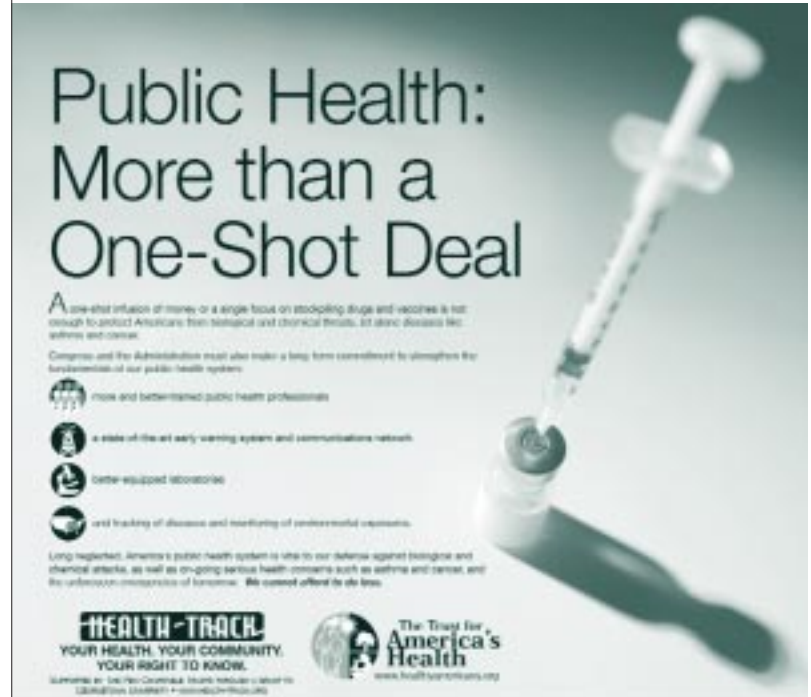
American College of Preventive Medicine	Association of Public Health Laboratories	National Association of Local Health Officers
American Medical Association	Health Trusts	Physicians for Social Responsibility
American Public Health Association	National Association of County and City Health Officials	Public Health Foundation
Association of Schools of Public Health		Trust for America's Health

HEALTH-TRACK

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PUBLIC HEALTH: MORE THAN A ONE-SHOT DEAL




Preparing for the budget battle in 2002, TFAH sponsored another print ad in the same papers before Congress adjourned in December. Competing funding priorities will make the fiscal year 2003 budget process difficult, so TFAH is ramping up its efforts to ensure public health funding needs are met.



**Public Health:
More than a
One-Shot Deal**


A one-shot infusion of money or a single focus on stockpiling drugs and vaccines is not enough to protect Americans from biological and chemical threats, or alone address the violence and crime.

Congress and the Administration must also make a long-term commitment to strengthen the fundamentals of our public health system:

-  more and better-trained public health professionals
-  a state-of-the-art early warning system and communications network
-  better-equipped laboratories
-  and tracking of disease and monitoring of environmental exposures.

Long neglected, America's public health system is vital to our defense against biological and chemical attacks, as well as on-going serious health concerns such as asthma and cancer, and the unforeseen consequences of terrorism. **We cannot afford to do less.**

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“We cannot just stockpile drugs without making a long-term commitment to such fundamentals as early warning systems and communications networks. These investments would improve our capacity to detect and respond to the bioterrorist attacks we are fighting today, unforeseen emergencies of tomorrow and everyday health crises.”

-Lowell Weicker, Jr., president of the board of directors of TFAH and former 3-term U.S. Senator and Governor of Connecticut, in a letter to the editor printed November 12, 2001 in The New York Times, echoing the need for a “long-term commitment” to public health infrastructure.

Many people believe what scientists and public health officials already know—the environment has significant impact on our health. Consider asthma, the most common chronic disease among children. Researchers do not know the cause of asthma, but they've proven that several environmental risk factors, such as dust mites, cockroaches, environmental tobacco smoke and ozone can trigger asthma attacks.

Many chemicals present in the environment have been shown to cause cancer at high exposure levels. The effect at low levels in the environment is unknown.

While we know that the number of people suffering from asthma and many other chronic illnesses has risen, public health officials do not have enough information to know why or how to prevent them.

TFAH has identified this gap in our public health knowledge and made strengthening the U.S. public health system through increased federal resources one of its major objectives in 2002.





Prior to the establishment of TFAH, the Pew Environmental Health Commission at Johns Hopkins School of Public Health concluded that local, state and federal health officials need more tools to prevent chronic illnesses. The Commission called for the establishment of a Nationwide Health Tracking Network. Such a network would give communities the information they have a right to know: when and where diseases such as asthma and cancer occur and their potential links to environmental hazards.

TFAH's primary campaign this past year has been advocating for resources for a nationwide health tracking network.

With a coalition of environmental health groups—Health-Track, Physicians for Social Responsibility, U.S. PIRG, and The Center for Children's Health and the Environment at Mount Sinai—TFAH successfully worked to get Congress to fund environmental health tracking.

Almost \$30 million were approved by Congress in fiscal year 2002 appropriations to begin the health tracking network.

This funding is a down payment on the \$275 million—about \$1 for every American—needed to implement the network nationwide.

SEPTEMBER 11 AND THE NEED FOR HEALTH TRACKING

Widespread concern about unique environmental exposures suffered by relief workers at the World Trade Center and the Pentagon after September 11 heightened officials' interest in ways to monitor health and environmental factors.

Shocked by the limited health information in existence—after the attacks, public health officials had to rely on surveillance of emergency room visits and pharmaceutical sales of anti-diarrhea medication to monitor any unusual illnesses—policymakers saw the gap in the tools available for safeguarding public health.

TFAH used this striking example to show members of Congress the importance of disease tracking and monitoring of people's exposures to hazards in the environment.

Congress, in its fiscal year 2002 spending bill, funded the very first health tracking pilot project. Twelve million dollars have been dedicated to track the health of the September 11 responders and relief workers.

News articles have detailed many residents' and workers' fears that the air in lower Manhattan might be making them sick. The Washington Post reported that tests by the Environmental Protection Agency have found elevated levels of toxic substances such as dioxin, PCBs, lead and chromium in the air, soil and water around Ground Zero.

Comprehensive tracking of illnesses and exposures to these environmental hazards could provide public health officials and communities important health information. A nationwide health tracking network is needed now to help provide answers for these health concerns, as well as the serious concerns nationwide about the alarming increase in rates of asthma and other chronic diseases.

A SNAPSHOT OF HEALTH TRACKING SUCCESS

TFAH HAS:

- Organized a coalition of 27 health and environmental groups to sign a letter to Congress calling for funding of a health tracking network.

- Worked with leaders of the Congressional Black Caucus, recruiting a total of 30 Caucus members to request support for health tracking from congressional appropriators.

- Circulated a letter to Congress from 41 physicians calling for federal appropriations for disease tracking.

- Spearheaded efforts of more than 14 national groups requesting higher funding of a health tracking network in fiscal year 2002 appropriations. Groups signing the letter include: American Lung Association, American Public Health Association, and National Association of County and City Health Officials.

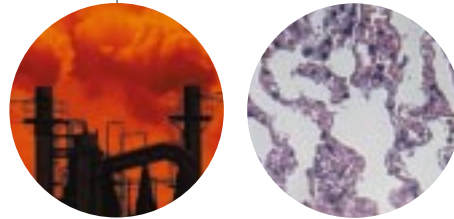


WORKING WITH CDC:

Adding to congressional support for the nationwide health tracking network, TFAH has worked with the Centers for Disease Control and Prevention (CDC) to ensure that health tracking as outlined by the Pew Environmental Health Commission (PEHC) is an important initiative within the agency.

In August 2001, CDC officially responded to the call for environmental health tracking by releasing its plan for tracking chronic diseases and environmental factors that may be linked to them. CDC's proposal closely follows the tracking framework identified by the PEHC.

In addition, TFAH staff regularly work with CDC's experts to ensure the tracking plan meets the previously identified needs. TFAH staff participate with other health and environmental leaders in a series of CDC-sponsored technical workgroups as the agency works toward implementation of the health tracking network.



RESOURCE FOR LAWMAKERS,
ADVOCATES FOR PUBLIC HEALTH

Throughout the health tracking campaign, TFAH has been an invaluable technical resource to policymakers.

— TFAH drafted model legislation, which served as a key resource for a bipartisan group of several U.S. Senators and Representatives who plan to introduce health tracking legislation in early 2002. Called the HEARRT Act, the Health and Environment Assessment, Rapid Response and Tracking Act, the legislation will provide momentum to health tracking while TFAH continues its push for additional appropriations.

— Early in the fiscal year 2002 congressional budget process, former Congressman Louis Stokes, a member of TFAH's board of advisors, testified before the House of Representatives' Labor Health and Human Services, Education and Related Agencies Appropriations Subcommittee on the need for a nationwide health tracking network.

— At the request of the U.S. Senate, TFAH Executive Director Dr. Shelley Hearne provided expert testimony during a Senate Environment and Public Works Committee field hearing. In Fallon, Nevada, state newspapers carried Hearne's message about the gaps in the public health system and the need for more information to better understand the region's childhood leukemia cluster.

— U.S. Senator Hillary Rodham Clinton (D-NY), in a nationally broadcast speech to the National Press Club, listed establishing a comprehensive national tracking system for chronic diseases as the number one priority for fighting hidden health hazards. She credited Trust for America's Health for its health tracking advocacy efforts. In her speech, Clinton called for creating a "chronic disease rapid-response force, as advocated by the Pew Commission and the Trust for America's Health."

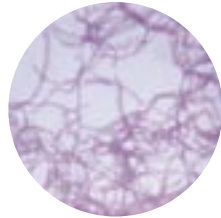
— Many state legislatures understand the need for tracking diseases and monitoring exposures to environmental hazards to prevent illnesses, and have acted in the past year. In California and Montana, for example, TFAH provided technical assistance in various areas for the state laws passed in 2001 to set up tracking systems. Working with the National Conference of State Legislatures, TFAH will continue providing resources for state tracking efforts.

Congressman Louis Stokes



NEWSPAPERS AROUND THE COUNTRY
VOICE NEED FOR HEALTH TRACKING

In its first year, TFAH has worked to educate the public about health tracking. As a result of TFAH congressional testimony, staff interviews, editorial board visits, and fact sheets, regional media have reported widely on health tracking. A sample of what newspaper editorial boards are saying:



“Fortunately, Congress is taking steps to bridge the disturbing lapses in health information systems. Tucked into the House health appropriations bill is \$20 million to lay the foundation for a nationwide health-tracking network.”

-The Oregonian editorial, October 26, 2001

“The health tracking network must be established as quickly as possible.”

-San Antonio Express-News editorial, November 1, 2001

“...the nation wants to prepare for fending off diseases associated with terrorism, but at the same time Congress should not let the basic needs of our public health system go unmet.”

-Las Vegas Sun editorial, November 5, 2001

TFAH RELEASES “SHORT OF BREATH” REPORT

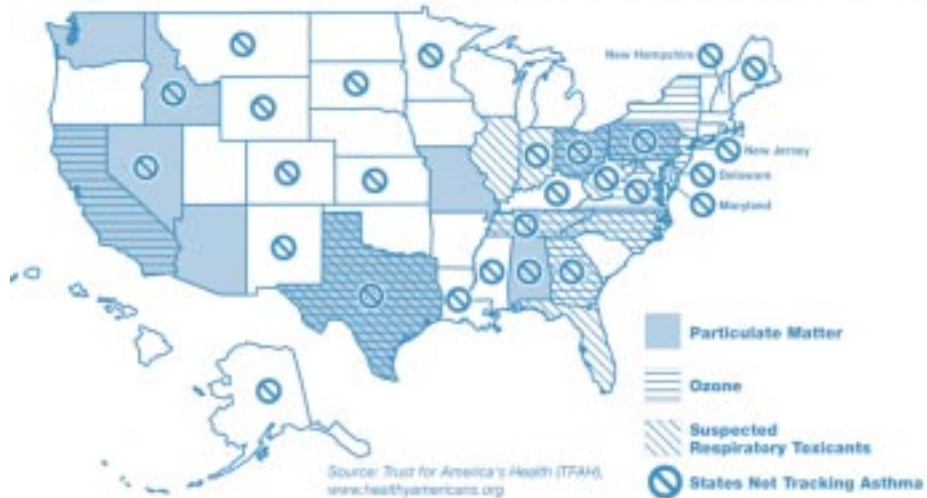
To bring the need for more health information into focus for communities and state health officials, TFAH released a scientific report that provided state-level data on asthma tracking. The Trust’s first major report, *Short of Breath: Our Lack of Response to the Growing Asthma Epidemic and the Need for Nationwide Tracking*, analyzed state-specific data and showed that 12 of the 20 states with the highest air pollution known to affect asthma do not track the disease at the state and community levels.

Asthma affects more than 17 million Americans—including nearly 5 million children. Information gained through tracking and monitoring the disease could help better prevent it in the future.

Partnering with local allies and national coalition members, TFAH maximized each group’s resources. For example, John Kirkwood, chief executive officer of the American Lung Association (ALA) was quoted in the TFAH release, along with representatives from ALA’s state chapters and doctors from Physicians for Social Responsibility. TFAH news releases with state-specific information spurred interviews with local allies and more regionalized stories on the need for asthma tracking as part of a comprehensive nationwide health tracking network.

Media coverage of the report was impressive. Among the stories, *USA TODAY* printed an article on the TFAH report with the headline: “Asthma Tracking Urged.” Several additional stories ran in major regional and state newspapers, as well as on 31 television stations—many in top markets, such as New York City’s WABC-TV—and on radio stations across the country.

Highest Air Pollution States and Asthma Tracking



TFAH OPENS HEALTHY AND GREEN OFFICE

TFAH officially opened its doors in Baltimore with an open house to celebrate its “healthy and green” office space. The office is built with reused materials and other products free of toxic chemicals known to cause eye and respiratory irritation. Located in a refurbished historic office building on Water Street in downtown Baltimore, the TFAH offices were built by STUDIOS Architecture, which donated its time and persuaded several companies to also provide materials for the space. TFAH also has an office in downtown Washington, D.C.

Terrie Miller, TFAH Board of Directors; Cynthia Harris, TFAH Board of Directors; Shelley Hearne, TFAH Executive Director; Lois Banks, TFAH Director of Community Health; and Tim Kearney



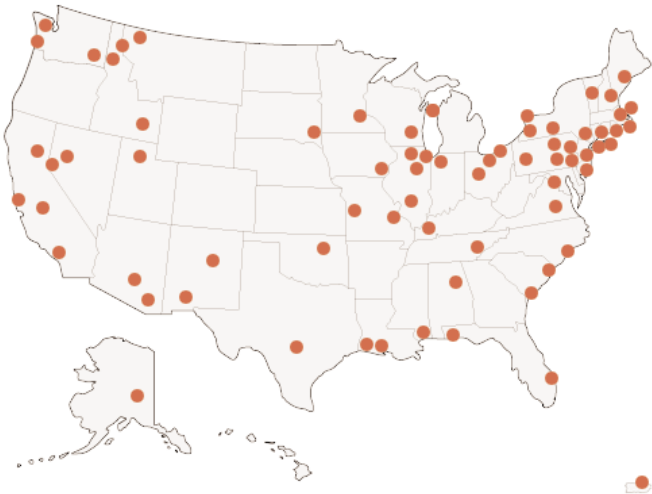
Public health officials need more information to fight chronic diseases, and communities have the right to know what might be making them sick.

TFAH is committed to helping local groups make their voices heard and to ensuring that communities have the resources they need in their battle against chronic diseases. To achieve this, TFAH launched the Community Health Forum in October. The Forum asks members of communities across the country to share their stories about health issues affecting them.

At www.healthyamericans.org/forum, individuals can post concerns about disease clusters and environmental hazards in their area and document important health issues. From the site, people can also send letters to their Senators and Representatives about the need for nationwide health tracking.



DISEASES CLUSTERS & CONCERNS



Analyzing news stories around the country about community concerns with disease clusters, TFAH mapped the clusters on its website. Each community has a page describing its concerns and how disease tracking and monitoring of environmental exposures could help provide that community and public health officials with more and better information to prevent future illnesses.



From the beginning, TFAH has made it a priority to reach out to communities around the country. In order to meet its goal of helping families and communities, TFAH staff work with a number of people who are doing extraordinary things in the fight against chronic diseases and for more public health resources. To highlight their stories, profiles of these courageous people will appear regularly on the TFAH community profile page. Linda Lanier is the first profile on the website.



Linda Lanier

One Woman's Battle with Mysterious Disease Shows Need for Health Tracking System

Linda Lanier is living with a mysterious, debilitating disease called sarcoidosis. More information could lead to better prevention, awareness and even a cure. That's why Linda Lanier and her family support efforts to establish a Nationwide Health Tracking Network, which would improve our ability to track chronic diseases like sarcoidosis and monitor environmental factors that may be linked to them.

Linda's Story

In 1979, as a college student in Washington, DC, I was diagnosed with a mysterious disease called sarcoidosis. No one knows why I contracted this disease. In fact, little is known about it, and because it mimics other diseases, it is often misdiagnosed. As a result, many sarcoidosis sufferers receive improper or delayed treatment.

As a young black woman, I was especially at risk. In the United States, sarcoidosis affects 40 out of 100,000 Black Americans, compared to 5 in 100,000 Whites. African-American women are twice as likely to contract the disease as African-American men. No one knows why. The disease also appears to be more common and more severe in certain geographic areas, such as cities on the East Coast (20 cases per 100,000). Again, no one knows why.

Sarcoidosis causes the body to create small lumps of inflamed tissue, called granulomas, which become scar tissue and interfere with organ function. The most common manifestations are in the lungs, skin, joints, eyes, central nervous system, heart, liver, kidneys, lymph glands, and other soft tissue organs. The disease has been linked as a contributing factor to other health problems, such as diabetes, blindness, hypertension, and heart attacks. It is not contagious and there is no known cure.

Increased tracking of sarcoidosis could provide doctors and patients with the information necessary to find a cause and a cure. That is why I am actively lobbying for legislation to create a nationwide health tracking system that would collect, analyze, and report data on the incidence of chronic diseases, including sarcoidosis, and any potential links to environmental factors.

Despite my fatigue, I also spend a little time each week going door-to-door, asking my neighbors to sign a petition calling on Congress to take action on a nationwide health tracking network. Many of these days, my son Onajee, who has been so supportive, comes with me as I knock on doors in an attempt to increase signers. I also take the petition with me to my doctors' appointments and health forums, and regularly email members of the sarcoidosis awareness network urging them to join the effort.

I will never accept sarcoidosis as being a part of me nor resign myself to it. I believe I am next in line for that miracle that will release me from this suffering. In the meantime, we must meet this disease head on. Please join us!

THE YEAR AHEAD

Throughout the year, the Trust for America's Health will work with a variety of state and local groups concerned about environmental and health issues to host community meetings, release reports with relevant state health information, and continue calling for strengthening of the public health system.

TFAH will release a birth defects report analyzing birth defects tracking systems in all 50 states, the District of Columbia and Puerto Rico, with recommendations for minimum standards for tracking birth defects and conditions. With detailed state fact sheets and an interactive web site to display the state information, TFAH will communicate the benefits of investing in public health to state and local officials and community groups.

As the federal budget process continues throughout 2002, TFAH will reinforce this past year's successful activities and call for additional funding of the nationwide health tracking network so all 50 states can begin consistent, comprehensive chronic disease tracking to improve the nation's health.



FOUNDATION SUPPORT

Trust for America's Health is a non-profit organization founded by the Benjamin Spencer Fund in loving memory of Benjamin, whose compassion for others continues to guide and inspire us. TFAH is supported by The Pew Charitable Trusts, Joyce Foundation, Rockefeller Family Fund, March of Dimes Birth Defects Foundation, Bauman Foundation, Tortuga Foundation, Jenifer Altman Foundation, and Mitchell Kapor Foundation.

The opinions expressed in this material are those of the Trust for America's Health and do not necessarily reflect the views of these foundations.



Benjamin Spencer

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Congressman (R-IL), Retired in 2000 as Chair of HHS Appropriations
Committee

Louis Stokes
Former 15-term Congressman (D-OH), Squire, Sanders, and Dempsey

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Shelley A. Hearne, DrPH, Executive Director

Paul A. Locke, DrPH, JD, General Counsel and Deputy Director

Lois D. Banks, Director of Community Health

Ella Cain, Office Manager

Anna Dillingham, Outreach Specialist

Margo Edmunds, PhD, Director of Research and Policy

Amy Goffe, Director of Communications

Sudha Koduru, MHS, Policy Analyst

Clarissa Lee, Executive Assistant

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Mandy Guirguis Reynolds, Legislative Assistant



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