Breath of Life: Stories of Asthma From an Exhibition at the National Library of Medicine

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In asthma, the lungs suffer and the parts which assist in respiration, namely the diaphragm and thorax, sympathize with them.

Aretaeus the Cappadocian

Joey McCoy was 10 months old when coughing, wheezing, and shortness of breath first began to sap his energy. He struggled for years with breathlessness, and his brushes with death were frequent. Then, at age 6, in 1953, Joey left New York for Denver, temporarily forsaking his own home for the “home of last resort”—the Jewish National Home for Asthmatic Children. The founder of the Home was Dr. M. Murray Peshkin, whose approach to treating children with intractable asthma was “parentectomy.” Peshkin had observed that children with severe asthma often improved upon hospitalization, even before their medicines could take effect.

Peshkin told Newsweek in 1955 that “no matter how sympathetic and conscientious their relatives were,” children with severe asthma needed to get away from their homes.1 Maybe the trigger for asthma was the parents or other family members; maybe it was the dust and specific allergens in their homes; maybe both contributed. In any case, Peshkin had observed over many years that parentectomy was therapeutic. In Denver, children discovered the full capacity of their lungs again, functioned well with fewer medicines or none at all, and participated in sports, often for the first time in their lives. Joey, for example, had been transformed from a “skinny, pale youngster” to a “rosy and sturdy” member of the Home’s boxing team and, after a 2-year stay, was heading back to New York with his asthma under control. His parents, too, had been “rehabilitated” with the help of a social worker, who primed them for life with a child who was not sickly and did not need pampering.

The year Joey went to Denver, some 5 million people in the United States were suffering from asthma. Today the number has climbed to 15 million.

The extreme treatment—abandoning one’s home for a healthier environment—was then and is today available only to a privileged few. Instead, most asthma sufferers tussle with the disease while plowing ahead with their lives. The ones who get the disease under control, who successfully live with asthma, may lead perfectly ordinary lives or, in many cases, extraordinary ones. Beethoven, Elizabeth Bishop, Robert Joffrey, Edith Wharton, Djuna Barnes, Woodrow Wilson, Helen Hayes, Dylan Thomas, Augustus Caesar—all had asthma.

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The less lucky ones, those who cannot find the right combination of therapies and lifestyles, may be debilitated by the disease. Proust, for example, spent the last 12 years of his life in bed, but that afforded him the opportunity to write Remembrance of Things Past.

A third group, the unluckiest ones, die during asthma attacks.

**The Disease**

Asthma is an ancient ailment, and many ancient languages—Sanskrit, Greek, Yoruba, Chinese, Aztec, and others—had names or symbols for it, all denoting breathlessness. Societies of old approached the treatment of asthma holistically, combining herbal therapies, exercise, steam (sweat ovens, inhalation of herbs heated on hot bricks), cleansing of the environment or avoidance of polluted ones, and culture-specific strategies for restoring the body to balance, such as stimulation of certain acupuncture points or adjustment of 1 or more of the 4 humors. (Asthma sufferers were said to have too much phlegm, which accounted for their phlegmatic personalities.)

Most asthma sufferers today and those who care for them also approach the disease with a broad view, understanding that what induces asthma in each individual will be some idiosyncratic mix of genetic factors (genes that make the person susceptible or genes that affect the structure or functioning of the lungs, immune system, or endocrine system), environmental triggers (allergens, chemical irritants, infectious organisms), and stress (which sometimes exacerbates the disease and sometimes is exacerbated by it).

But off and on between those ancient times and now, doctors and other health researchers sought single etiologic agents—a defect or deformity in the lungs, a problem with nerves and emotions, a reflection of a pathologic physical or social environment (hence the finger-pointing pathologizations)—to account for the disease. The searches generated a comprehensive list of factors that synergistically, rather than individually, contribute to suffering in asthma.

**The Treatments**

Regardless of what might be inducing asthma, both patients and physicians had to find ways to deal with asthma’s wrenching symptoms. The signature physiologic changes that accompany asthma attacks are inflamed and swollen airways, constrictions in the muscles that are associated with the airways, and mucus production, which further plugs the airways.

Healthy airways might be compared to stalks of broccoli ringed with a few thick rubber bands—the muscles. Alveoli, the lungs’ tiny out-pouchings through which gases in the air pass to the blood, resemble the broccoli florets. When asthma strikes, the rubber band muscles constrict, the stalk metamorphoses from broccoli to linked sausages, and the bulbous alveoli expand like balloons about to burst. Oxygen flow through the airways is impeded under these conditions, and wheezing and coughing ensue. Various pharmacologically active agents can counteract these changes, decreasing the swelling and inflammation and relaxing the constricted muscles. The airways can then stretch and реinflate, and oxygen can flow again.

Both designer synthetic drugs—anti-inflammatories and bronchodilators—and more traditional medicines can produce the necessary ameliorative effects. And, in fact, many modern drugs are extracted from or modeled after the natural ones. For example, the drug Intal contains the compound sodium chromoglycate, an anti-inflammatory compound extracted from the herb khellin, which the Egyptians brewed into a therapeutic soup 5000 years ago. Theophylline, which is similar to caffeine, is a bronchodilator extracted from coffee beans, which have long been known to provide relief from asthma. (The 1786 Edinburgh New Dispensatory described coffee or “Coffea” as “the fruit of an oriental shrub … employed rather as food than as a medicine. The medical effects expected from it, are to assist in digestion, promote the natural secretions, and prevent or remove a disposition to sleepiness. It has been recommended in spasmmodic asthma.”) Scientists isolated ephedrine from the Chinese herb ma huang 100 years ago and extracted adrenaline from animal adrenal glands at roughly the same time.

Credit for Intal goes in part to Dr Roger Altounyan, who isolated sodium chromoglycate in 1963. Altounyan purified and tested some 700 chemical compounds over an 8-year period before he happened on the one that worked. His approach was to test each compound on himself, because he suffered from asthma. He would inhale a compound and then challenge his airways with guinea pig hair, to which he was allergic. Altounyan chose to become his own guinea pig, concluding that the real ones were not ideal models in which to evaluate potential drugs for humans.

Some 20 years later, Altounyan made a second critical contribution to asthma therapy. He invented the “spinhaler,” the prototype for contemporary inhalers, nebulizers, vaporizers, and atomizers. Altounyan had been a pilot in the Royal Air Force and reasoned that, just as airplane propellers spin in drafts, miniature propellers inside medicine bottles could impel drugs into the lungs when a person inhaled. The coordination of drug delivery and breathing would, in fact, be automatic. (Altounyan said he got the idea for the device one day in his bath while pondering the “principle of the propeller.”)

Delivering medicines to the tissues that need them is almost always as daunting a challenge as finding pharmacologically active substances, so the spinhaler was a significant technologic breakthrough. Ironically, its precursors were various cigarettes and pipes that patent medicine companies promoted for delivering asthma-relieving herbs and compounds to fragile, compromised lungs.

A handful of other simple devices and techniques helped physicians refine the diagnosis and treatment of asthma over the years. Spirometers, manometers, and respirators sprang up during the 19th and 20th centuries, all of which measured breath volumes and lung capacities. Also in the 19th century, René Laennec, embarrassed to lay his ear on the chest of a woman patient while her family watched the examination, rolled up a piece of paper and listened to the woman’s heart through the cylinder. Voilà: the first stethoscope and a clearer impression for the doctor of the sounds that emanate from congested airways. In the 18th century, Leopold Uenbrugger tapped on the backs of his asthma patients to determine if their lungs were filled with air or fluid. His inspiration came from observing the percussive differences between empty wine casks and those filled with wine. In the late 17th century, Sir John Floyer counted his patients’ pulses with a watch in his hand, thus for the first time attaching numbers rather than imprecise names—“weak,” “fast,” “racing”—to pulse rates. He could then compare his measurements with those made by other doctors and could document changes in his patients as time went by.

**The Air**

From the time Joseph Priestley discovered oxygen in 1775, people realized that without oxygen, asthma sufferers (and anyone else deprived of air) would die.

One of the most devastating examples in the United States of the importance of clean air for sustaining life was the “Donora Smog.” On October 26, 1948, a temperature inversion over Pennsylvania’s Monongahela River trapped dangerous emissions—sulfur dioxide, carbon monoxide, and metal dust—
from the smokestacks of zinc and steels mills downriver from the town of Donora. The emissions turned into a sulfuric acid mist.

In Donora that night, the town’s children paraded in their Halloween costumes and Donora High School played and beat Monongahela High School in a football game. People who attended the game could not actually see the players or the ball on the field, but they could hear the whistles of the referees. By midnight, many people were violently ill. Within 4 days, 21 people were dead, half of the town’s 14000 residents had experienced crushing headaches, vomiting, cramps, chest pains, and breathlessness, and the toxic smog had wilted plants and killed pets. Those who were trying to assist others had to feel their way from building to building, because the smog was blinding. “If you chewed hard enough,” recalled one man who was there, “you could swallow it.”

The dead from the little mill town had all suffered previously from asthma or other respiratory ailments, and they died agonizing deaths from suffocation. “Nothing,” wrote the ancient Roman leader Seneca, “seems to me more troublesome [than asthma].” Seneca was writing about the effects produced by Mt Vesuvius, which, like the Donora mills, had spewed out sulfurous fumes, killed people throughout the Bay of Naples, and gone on to destroy towns.

The Donora Smog did have one positive effect: it served as the springboard for Pennsylvania’s first clean air legislation—passed in 1955—as well as the 1963 federal legislation on air quality, which was strengthened in 1970 to become the Clean Air Act.

Erupting volcanoes and Donora Smogs are, of course, extreme and atypical triggers of asthma. Most attacks are sparked by exposure to a single cigarette, seasonal pollens in the air, chemical irritants, cat dander in the home, cockroach leavings, and molds. People in certain professions sometimes face work-centered, asthma-inducing hazards, and this is nothing new. Bernardino Ramazzini, writing in Padua in 1713, described the occupational hazards for bakers from wheat and rye flour, of millers from grain dust, of farmers from animal dander, and of professors (I presume from musty manuscripts).

Some people, like Joey McCoy, are born with a susceptibility to asthma, but others acquire susceptibilities later in life. In Papua New Guinea, for example, asthma was unheard of until the 1960s, when men—and only men—began developing asthma in surprising numbers. Australian scientists who investigated the epidemic found that visitors to the villages had donated blankets and that the men had hoarded the blankets for themselves, balling them up at night for pillows. In the humid New Guinea climate, the makeshift pillows quickly filled with dust mites, and asthma became a fact of village life.

The Exhibition

As I walked around the National Library of Medicine’s asthma exhibit, I wondered about the target audience for Breath of Life. I could imagine that scientists and physicians everywhere, as well as those from the National Institutes of Health, which shares the campus with the Library, would be interested in the history of this debilitat-
ing disease and the advances—medical, technological, and pharmacological—that have gotten researchers and asthma sufferers to where they are today. I could also see that the exhibition would have great appeal to historians, historians of science, antiquities lovers, and general lovers of learning (of which I am one), because it is rich in interesting historic documents, images, facts, artifacts, and medical arcana.

But, when I considered the figure “15 million,” which first appears on the opening panel of the exhibition next to Aretaeus the Cappadocian’s comment, I realized that the rightful audience for any asthma exhibition is those 15 million Americans and, more inclusively, the hundreds of millions of people around the world who have the disease.

Visitors to museums, like window shoppers, stroll along looking for displays that pull them in and speak to their interests and needs. Asthma sufferers who choose to visit an asthma exhibition surely will be seeking practical information that might help them understand and manage their crippling disease. Is this exhibition pitched appropriately for them? Does it provide the help they need?

Two computers in the Breath of Life exhibition offer visitors opportunities to find and print out information from some 50 asthma-related Web sites. These computers are great resources, especially because they are linked to a printer, but only for visitors with time and Web savvy. Few people come to museums expecting to do literature searches, and I think the exhibition also should be providing visitors with a range of ready-make pamphlets, booklets, and fact sheets that could be of help. Among these would be lists of toll-free numbers to call for clinical information and clinical trials, copies of publications with “action plans” for coping with symptoms or helping someone else who is in distress, checklists for ways to make homes and workplaces safer, lists of behaviors that promote health, names and numbers of organizations that provide support and services for people with asthma, instruction sheets on how to use nebulizers, numbers to call and places to write to influence public policy on environmental pollution, and so on. The exhibition actually tantalizes visitors with numerous booklets, many or all of which are free government publications—What You and Your Family Can Do About Asthma, Asthma in the Elderly, Controlling Your Asthma, Asthma Management in Minority Children, Asthma and Physical Activity in the School, Pocket Guide for Asthma Management and Prevention, Guidelines for the Diagnosis and Management of Asthma—but these are firmly glued to the exhibition walls, not there for the taking.

Currently, visitors can walk away with just 2 fact sheets: The Immune Response in Asthma and Asthma: A VIP List. I always enjoy pondering imponderable numbers, like the 1 trillion cells that take part in the immune response. And I can see that some asthma sufferers might benefit from knowing the exact steps involved in an asthma attack—how an allergen will mobilize T and B cells and macrophages, how the cells will interact to produce allergen-specific IgE, and how the IgE–allergen complex will induce mast cells to release histamine and trigger asthma. At a minimum, this handout could show people how the various players—T cells, IgE, antihistamines—that they’ve heard about in ads and in conversations with physicians all come together to make them sick.

As for the information about celebrities who have or had asthma, a few people may find this inspiring, but, in reality, few museum visitors will actually end up becoming, or will even want to become, president of the United States, star athletes, or great performers or composers. A comment at the entrance of the exhibition by John Updike—“An asthma attack feels like two walls drawn closer and closer, until they are pressed together”—resonates, not because it was made by a famous author, but because it conveys a painful truth.

The Sesame Street video, an obvious magnet for the tiniest visitors to the exhibition, does for kids exactly what I wish the exhibition would do for adults. The Bert-and-Ernie gang members learn about asthma...
through their friend Dani, who gets short of breath while playing. The segment ends with Dani singing “And if it looks like I’m not okay, get a grownup right away.” They call it an action plan, and they review it several times. The instructions are not complicated, but they could save a life.

The most edifying drawings in the exhibition are on a flip chart—part of the American Lung Association’s 1998 Open Airways for Schools project—depicting the changes that occur in the airways during asthma, which I described above using the broccoli metaphor. When I first looked at those illustrations, I felt a catch in my own breath. (I do not have asthma.) I could see why asthma would be terrifying and why it might be hard to breathe deeply or at all when an attack begins.

The most telling sound bites were the two that juxtaposed the sounds made by healthy and asthmatic lungs. The healthy lungs’ long and steady inhalations and shorter exhalations were smooth and regular. The repeating cycles were controlled and even. Then came the sounds of the lungs of a person with asthma. The inhalation was deeper and the exhalation was heavy, long, and sloppy. Before the exhalation ended, a third, higher, raspier aftersound came on, redolent with dysfunction and distress.

I wish the airway flip chart and the lung sound bites had been positioned right at the entrance to the exhibition where all visitors would encounter them. Had the sound bites been accessible through a stethoscope-shaped headphone rather than standard earphones—wow! Right there, too, I wish the museum had hung the poignant poster produced by the National Asthma Education and Prevention Program—“Kids have a lot of energy. Some of them need it just to breathe.” That combination right up front would have constituted a real draw.

People drained by illness are looking for understanding, sympathy, and empathy, and they treasure finding kindred spirits. That’s why personal stories always are more powerful than facts and artifacts. The 2 stories that I particularly liked—Joey’s story and the story of Donora—were not exactly featured in the exhibition, although I became aware of them there. Only the first page of the Newsweek article about Joey is on display, in a case called Emotions and Asthma. I later stopped at the public library to read the full story. Similarly, my interest in Donora was merely piqued at the exhibition through a montage of 6 newspaper headlines on a poster in the case called Sick Places and Safe Places. That story, too, I had to research outside, because the exhibition provided no amplifying details.

Oddly, the longest single story in the exhibition is that of “Erica,” who developed asthma at age 4 and is tracked until she graduates successfully from high school. The display includes sound bites from Erica and her parents, their letters and other documents, and photographs of emergency rooms, workplaces, and so on. But none of this works, because the Erica panel begins with a clear disclaimer—Erica is fictional, a composite developed by a doctor. With 15 million true stories to choose from, I can’t imagine why the museum featured a fictional one.

During the approximately 6 hours I spent at the exhibition on several days reading every word, examining every artifact, and looking for good stories, few other people stopped by Breath of Life and no school groups came through at all. And yet, one wonderful photograph in the exhibition shows a Bronx classroom, #4-512, in which someone has asked the question, “Who has asthma?” Almost 50% of the kids have their hands raised high and so does the teacher. Why this disconnect?
Asthma is not a disease of the past. It is still with us, still consuming lives, energy, money, time, resources. It is cross-cultural, international, on the rise, and worse than ever. The *Breath of Life* exhibition contains wide-ranging, useful information and intriguing stories, but too much of the valuable material is academic and buried in a lifeless setting. Put simply, the exhibition could use a breath of life. Any public institution that chooses to install a medical exhibition has a golden opportunity to reach out to sufferers and others—to teach, to enlighten, to really do some good. More than an opportunity, it may also have an obligation. But, to succeed, it must always hold the perspectives of visitors foremost in mind.

Asthma stories should be stories of people. Aretaeus the Cappadocian said that the lungs suffer in asthma and the abdominal parts sympathize. But actually, it’s the people who suffer with asthma, and sympathy—in the form of concrete help—should be forthcoming from their public institutions.

The *Breath of Life* exhibition will remain on display at the National Library of Medicine (NLM) until March 2001. Guided tours of the exhibition are offered each Wednesday, with special group tours by request. For information about tour programs and future exhibitions, contact the NLM exhibition educator, Jiwon Kim, at 301-496-5963 (e-mail: jwon_kim@nlm.nih.gov).

The Library may be reached via the Washington, DC, Metro underground railway system. Visitors to the Library are encouraged to use Metrorail or Metrobus service on weekdays. The Library is 2 blocks south of the Medical Center stop on the Metro red line. Upon exiting the escalator, proceed south (left, and parallel with Rockville Pike) approximately 200 yards, or take the free shuttle bus to Building 38.

There is an on-line version of the exhibition at http://www.nlm.nih.gov/hmd/breath/breathhome.html. A related exhibition will open in Chicago in May 2000 at the American Academy of Physician Assistants and will be available to travel elsewhere thereafter.

References