

# Medical Genetic Research on the Amish: From Genetic Tourism to Community Health Centers

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In the 1960s, Victor McKusick inaugurated the Amish medical genetic tourist research program in order to learn more about the relationship between genes and human disease. However, Amish mistrust of outsiders and frustration at being exploited by tourism, as well as other cultural and historical factors, would ultimately result in the transformation of medical genetic research paradigms from genetic tourism to community health centers. Over time, Amish community health clinics, partially funded by the Amish themselves, were estab-

lished in Pennsylvania and Ohio. These clinics, which are long-term centers dedicated to primary care and advanced medical genetic research, give the Amish a sense of agency. Doctors from these clinics have achieved numerous medical breakthroughs that were possible only as a result of their long-term care of patients. This transition to Amish community health clinics illustrates the successes science and medicine can achieve when they are sensitive to unique population needs.

## MEDICAL GENETICS AND ISOLATED POPULATIONS

The field of medical genetics was initially threatened by the memory of the Nazi eugenic atrocities of World War II, which made United States geneticists in the 1940s wary of conducting genetic research on humans. Despite this historical baggage, by the late 1950s and early 1960s medical genetics had begun to emerge as a distinct field for scientific inquiry in the United States. In 1957, a professor of medicine, Victor McKusick, formed the medical genetics department at the Johns Hopkins Hospital (Harper, 2008). This department aimed to integrate clinicians and geneticists for the purpose of mapping (that is, identifying) the genes associated with or responsible for human diseases, as well as finding the chromosomal locations of these genes. In order to organize this information, in the early 1960s McKusick created Mendelian Inheritance in Man (MIM), which catalogs various disorders and the genes responsible for them. The online version of MIM (Online Mendelian Inheritance in Man) was set up between 1985 and 1987, and it is freely available through the National Center for Biotechnology Information website (McKusick, 2007).

In the beginning stages of this medical genetic research program, researchers realized that certain ethnic populations have different frequencies of particular genetic diseases; this would prove useful for relating genotype to disease phenotype (Harper, 2008). As a result, over the years scientists have conducted genetic studies on various isolated groups, including Ashkenazi Jews and the Amish. In particular, genetic studies on the Amish, which began in the 1960s, significantly shaped medical genetics in its infancy as a distinct field.

In the 1960s, medical genetic research on the Amish was conducted by “genetic tourists”—visiting university researchers touring the Amish country for short-term genetic research projects funded by their home universities or outside research grants. Yet the extremely closed nature of the Amish community proved a chal-

lenge to visiting researchers, who could not form deep, long-lasting ties with the community and were seen as outsiders. This challenge was exacerbated by the Amish affinity for alternative-medicine practices. Moreover, unlike other American minority groups, the Amish are educated only through the eighth grade; thus there are no Amish doctors or scientists who can help lead such research studies, to give the Amish community a sense of agency (Hostetler, 1993). As a result of these unique community needs and circumstances, over time the medical genetic research program on the Amish has shifted from being conducted by visiting genetic tourists to being performed by physician-scientists at self-sustaining Amish community health centers. Today, two Amish community health clinics exist—one in Lancaster County, PA, and another in Geauga County, OH. These clinics, which are partially funded by the Amish community, give the Amish a sense of agency by allowing them to help set the clinics’ research priorities. And while some genetic tourist studies continue, these visiting researchers often collaborate with physician-scientists at the clinics in order to facilitate their short-term research projects and earn the trust of the Amish.

## HISTORY, RELIGION, AND CULTURE OF THE AMISH

In the field of medical genetics, studying ethno-religious groups such as Ashkenazi Jews and the Amish often presents historical and cultural obstacles. The fundamental religious precepts of the Amish, which advocate separation from the world and mistrust of outsiders, initially presented a barrier to medical genetic researchers. The Amish of Lancaster County are descendants of about two hundred Swiss-German Anabaptist (adult baptism) settlers, who went to Pennsylvania beginning in the 18th century seeking religious freedom. Their native language is a German dialect called Pennsylvania Dutch, and they refer to outsiders (the non-Amish) as “the English.” It is extremely uncommon for a member of “the English” to join the Amish; the sense of separation is intense. This separation is exacerbated by the Amish rejection of mod-

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ern technology, as they refrain from owning or driving automated vehicles, as well as from using electricity in their homes. This sense of separation from the world is intentional and based on religious scripture. According to professor and historian John Hostetler, the Amish view themselves as a unique, chosen people who must evade the lustful, materialistic “English” world (Hostetler, 1993).

As a result, today the Amish are viewed by many as a “moral model” for their strict, disciplined rules of morality and rejection of many modern technologies. This perceived moral elevation has sparked intense curiosity toward the Amish and increased tourism in Lancaster County. Donald Kraybill, John Hostetler’s successor as the foremost historian of the Amish, explains that tourism has transformed the Amish “from despised heretics into esteemed objects of curiosity . . . oddly enough, the more separate and unusual the Amish appear, the more attractive they become” (Kraybill, 2001).

This attraction has resulted in a booming tourist enterprise in Lancaster County. Today about four million tourists visit the county annually, where they spend a combined \$1.2 billion (Kraybill, 2001). This flourishing tourist industry is evidenced by the hotels, family-friendly restaurants, stores claiming to sell “authentic” Amish goods, amusement parks, and Amish-themed attractions intended to satiate the throngs of tourists.

While the hordes of gawking tourists may be irritating to the Amish, it is particularly the Amish-themed attractions and stores that they view as culturally and economically exploitative, because the bulk of these Amish-themed enterprises are owned by non-Amish businesspeople capitalizing on the Amish community’s religious and cultural practices. Such exploitative attractions include competing buggy-ride companies, tours of “authentic” Amish farms and homes, and even an “Amish-experience theater.” At the same time, the Amish are finding ways to benefit economically from this tourism, particularly through the establishment of roadside stands that sell foods and goods to tourists (Kraybill, 2001).

This multifaceted dynamic resulting from the tourist industry, as well as the intense Amish desire just to be left alone, results in a latent tension between the Amish community and individuals who capitalize on their unique culture for profit. This tension erupted in controversy in 1984, when the major Hollywood film *Witness* was filmed in Lancaster County. Harrison Ford plays Philadelphia police officer John Book, who is investigating a murder whose sole witness is a young Amish boy named Samuel Lapp. Circumstances force Officer Book to hide out disguised as an Amishman in Lancaster County, and eventually he and Samuel’s widowed Amish mother develop romantic and sexual feelings for each other. The film also features a violent shootout on the Lapp family farm (Kraybill, 2001).

The movie’s infusion of sex and violence into its depiction of Amish life was offensive for many Amish, as they believed it misrepresented their peaceful, modest culture (“Amish Feelings Mixed,” 1984). As a result, Amish bishops met with Pennsylvania state officials, and they eventually came to a written agreement; this agreement stated that Pennsylvania would not seek to promote the Amish as subjects for TV or films, though the state could not prevent movies or shows from depicting the Amish or filming in Lancaster County (Beale, 1985).

This incident illustrates the depth of the Amish community’s inherent mistrust of outsiders. And this sensitivity to “the English” also highlights the extreme obstacles medical geneticists in the 1960s had to overcome in order to inaugurate their genetic tourist research programs. While such research was successfully performed, over time the latent cultural sensitivities necessitated the establishment of long-term Amish community health centers.

### GENETIC TOURISM AND VICTOR MCKUSICK

The irony of Amish tourism—that the more separate the Amish become, the more attractive they become to outsiders—provides an important parallel to the practice of Amish genetic tourism. The more separate the Amish become, the more isolated their gene pool is, and thus the more distinct their characteristic genetic disorders are from the disorders in the “English” population. This different profile of disorders is important to geneticists, as investigating these otherwise rare disorders that are common in the Amish allows the researchers to learn more about the functions of the genes involved. This is possible only because of the large concentration and relatively high number of patients with the disorder of interest present in the Amish population (McKusick, 1978).

This distinct genetic disorder profile results from the founder effect and genetic drift, as well as from the negligible gene flow into the Amish population. This essentially means that because the Amish started with a small group of about two hundred founders, only the alleles present in the founders will be present in the succeeding generations. And because the Amish have a negligible number of “converts,” the homogeneity of the Amish genetic pool over time is exacerbated by the limited introduction of new alleles into the population (McKusick, 1978).

As a result, the present-day Amish population exhibits a characteristic profile of genetic disorders that are present in (or notably absent from) the population. For example, the Lancaster County Amish have a high frequency of the disease glutaric aciduria type 1 (GA1), which is an autosomal recessive metabolic disorder. GA1 leaves the body unable to properly break down proteins into amino acids, causing glutaric acid (an intermediate in

the degradation process) to accumulate in high levels in the brain. In children under the age of two, this sudden, excessive accumulation of glutaric acid can cause permanent basal ganglia brain injury. This leaves children permanently neurologically damaged, unable to speak, eat, or walk for the rest of their lives (Belkin, 2005). These genetic population conditions make the Amish an ideal study group for medical geneticists seeking to learn more about the function of various genes in the human body, as well as how these genes contribute to human disease. The Amish also benefit from genetic tourism, as the research findings aid in the diagnosis and treatment of disorders that plague the Amish community.

The first of the Amish medical genetic tourists was Victor McKusick, renowned as the “father of medical genetics” (Harper, 2008). McKusick’s interest in the Amish was initially piqued by an informal 1962 pharmaceutical pamphlet, which contained an account of dwarfism in the Amish by Lancaster County physician David Krusen. A few months later, McKusick’s curiosity was further stimulated. While serving on a committee advising the Johns Hopkins University Press in 1962, he received a manuscript for historian John Hostetler’s book *Amish Society*. McKusick was immediately fascinated by the “closed nature of the Amish,” as well as the aforementioned Amish population genetic conditions, which impressed him “as useful characteristics for genetic studies, particularly of recessive traits” (McKusick, 1978). McKusick and Hostetler, along with sociologist and behavioral scientist Janice Egeland, formally detailed their research intentions in “Genetic Studies of the Amish: Background and Potentialities,” which appeared in the 1964 *Bulletin of the Johns Hopkins Hospital*. The paper served as an overall justification for research on the Amish and a “call to arms” for further research. It asserted that the Amish were an ideal population for medical genetic study because of several characteristics: they are a clearly defined population, their ethnic origins are well known, they have extensive genealogical records, they have a relatively high standard of living (minimizing some environmental disease-causing factors), they are generally uniform in socioeconomic and occupational circumstances, as most are farmers (reducing environmental variability), and they have extremely large families (most have seven to nine children), which allows for large and extensive family genetic pedigrees (McKusick, 1978).

After issuing this “call to arms,” McKusick actively engaged in medical genetic research on the Amish—first in Lancaster County and then in other Amish communities, such as those in Ohio. McKusick went on to publish Amish population research on Ellis-van Creveld dwarfism, congenital recessive deafness, pyruvate kinase deficiency, cartilage-hair hypoplasia (CHH) dwarfism, Troyer syndrome, Mast syndrome, Byler disease, and McKusick-Kaufman syndrome. While some of these medical conditions had been previously described in other (non-Amish) populations, many of McKusick’s Amish studies marked

the discovery of new genetic disorders altogether. For example, in one of McKusick’s 1965 Amish studies, he and colleagues were the first ever to describe and characterize CHH; this is an autosomal recessive genetic disorder that results in dwarfism due to skeletal dysplasia. Similarly, in one of McKusick’s 1964 Amish studies, he and colleagues were the first to describe an autosomal recessive genetic condition that would later be branded McKusick-Kaufman syndrome. This syndrome results in polydactyly (extra toes or fingers), congenital heart disease, and in females the accumulation of fluids in the vagina and uterus (McKusick, 1978).

These Amish studies also have a storied place in the history of medicine, as they in part inspired the formation of McKusick’s MIM. In a 2001 interview, McKusick explained:

Then the Amish studies came along, and I wanted to collect a comparable catalog of autosomal recessive traits, because in that inbred population, we expected to find even new recessives that had not previously been recognized. And indeed we did. And to know the new ones, we had to know the old ones. Then for sake of completeness and with some trepidation, I assembled an autosomal dominant catalog. . . . Those [disorders] in which the particular mode of inheritance seemed to be quite well established, we gave an asterisk to; and those in which it was in limbo still, we left without the asterisk. Of course, this was MIM, this was Mendelian Inheritance in Man. (Maestrejuan, 2001)

Yet in establishing this important Amish research program, McKusick faced several obstacles resulting from the complex Amish dynamic with exploitative tourism and the Amish community’s sense of separation from the “English” world. To surmount these hurdles, McKusick enlisted the help of two local “guides”—John Hostetler and Dr. David Krusen. These guides, who already had long-standing ties to the Amish community and were well trusted, were able to facilitate McKusick’s research program (Lindee, 2005). The historian Hostetler was raised Amish, but left prior to adult baptism, meaning he was not “shunned” by the Amish church. (Only those who leave after baptism are shunned.) This meant that Hostetler was fluent in Pennsylvania Dutch and was intimately familiar with the cultural practices of the Amish (McKusick, 1978). Both Hostetler and Krusen were able to introduce McKusick to Amish patients and other individuals, as well as give McKusick the public stamp of approval within the Amish community (Lindee, 2005). This allowed McKusick to gain the trust of the Amish community, which he cemented in home visits to patients over the years; these home visits also allowed McKusick to generate accurate family disease pedigrees, as he could inconspicuously observe whether other family members exhibited symptoms similar to those of the affected patients. This was particularly significant because these accurate pedigrees, in combination with

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genealogical records, allowed McKusick to determine the mode of inheritance as well as the original Amish disease allele carrier (Maestrejuan, 2001). For example, in the case of Ellis-van Creveld dwarfism, McKusick was able to trace the disease allele back to Amishman Samuel King (or his wife), who immigrated to America in 1744 (McKusick, 1978).

Despite the remarkable medical advances the Amish reaped as a result of McKusick's home visits and research program, McKusick's research was fairly paternalistic and secretive in nature (Lindee, 2005). It was paternalistic in the sense that the Amish were denied a fundamental sense of agency; the priorities, progress, and findings of McKusick's research program were not available for review by Amishmen, who were not able to obtain or understand complex scientific research journal articles. Historian of science Susan Lindee explains, "McKusick did not particularly want the Amish who provided him with information and insights and with descriptions of their dead infants to see (or read?) the scientific papers he was publishing" (Lindee, 2005). In a letter written by McKusick to a Lancaster County physician, McKusick writes, "I am enclosing a reprint of our Ellis-van Creveld paper. I, of course, do not want it to get into the hands of our Amish neighbours" (Lindee, 2005). Though the Amish were intended to benefit clinically from McKusick's research investigations, they were not expected to comprehend or evaluate the research being conducted on them (Lindee, 2005).

McKusick's research program on the Amish had largely ceased by the late 1970s. After this period, a series of medical genetic tourists performed research on the Amish, whom they viewed as an ideal "guinea pig" population. However, the majority of these new genetic tourist researchers required the assistance of or introduction by either McKusick or Egeland, who had worked with McKusick on his early Amish studies and still lived in Pennsylvania. McKusick and particularly Egeland were required as collaborators in order to help new genetic tourists earn the trust of the Amish, just as McKusick himself had relied on Hostetler and Dr. Krusen as guides. For example, when Johns Hopkins genetic tourists Muin Khoury and Bernice Cohen sought to conduct several genetic epidemiological research studies on the Amish in 1987, they had to collaborate with McKusick. This collaboration allowed Khoury and Cohen to publish several papers on inbreeding and prereproductive mortality in the Amish, as well as on genetics and growth retardation in the Amish (Khoury et al., 1987).

A host of medical geneticists and behavioral scientists descended on the Amish beginning in 1983 in order to determine the genetic basis for bipolar disorder. All of these studies in some way involved collaboration with Egeland (Kidd et al., 1984). However, this system of required connections and collaborations with the same two people, the only bridges between the Amish and

the world of medical genetics, would simply be untenable in the long term. The later establishment of Amish community health clinics thus partially arose from the need to have a permanent base of operations for consistent, long-term research projects on the Amish. This base would also allow visiting genetic tourist researchers to latch onto the clinic for collaboration, in order to gain the Amish community's trust.

The utility of these permanent Amish community health clinics for visiting genetic tourists is typified by the case of University of Maryland medical researcher Alan Shuldiner. Shuldiner has published a series of type 2 diabetes studies on the Amish, with the hope of determining a genetic link to the disease. Though Shuldiner is a genetic tourist, he initially rented out space in the basement of Lancaster County's Amish community health clinic in order to conduct his research and recruit Amish subjects who were already comfortable with the clinic's work (Warmkessel, 2004).

### AMISH ATTITUDES TOWARD MAINSTREAM AND ALTERNATIVE MEDICINE

Genetic tourist researchers, who traditionally visit the Amish community for a short time, come with set research agendas determined and funded by outside universities or institutions rather than arising endemically from the population's immediate health needs. In addition, these researchers often leave without making long-term connections with patients. Thus they reflect the increasingly cold, scientific nature of modern Western medical care (Kleinman, 2008)—an aspect often troubling to the empathy-seeking Amish (Hostetler, 1993).

The Amish harbor no religious objections to advanced, high-tech medical procedures such as bone-marrow transplants. Hostetler explains, "Nothing in the Amish understanding of the Bible forbids them from using modern medical services, including surgery, hospitalization, dental work, anesthesia, blood transfusion, or immunization" (Hostetler, 1993). However, physicians who treat the Amish observe that they are relatively slow to seek out care and do not practice adequate preventive medicine; this can also be attributed to the long commute via horse and buggy, as well as the high cost of medical services for the Amish—many of whom are uninsured for religious reasons. The Amish believe it is the religious community's responsibility, not the responsibility of any outside organization or government, to care for the sick. For this reason, they are exempt from Social Security payments, and thus are ineligible for Medicaid or Medicare coverage. Some families do have Amish Aid plans, which function similarly to health insurance plans but are viewed as acceptable because they involve only mutual Amish aid. But many Amish families do not have such aid plans and must pay completely out of pocket for medical expenses; the church community helps them if they are unable to pay (Anand, 2008).



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When the Amish do finally seek out medical care, they look for trustworthy, empathetic physicians. This sense of trust is a fundamental part of how the Amish community operates on a day-to-day basis. A tight-knit community to begin with, Amish families are further connected by their organization into local church districts, in which each family in turn hosts Sunday church services at its home (Hostetler, 1993). In such personal, small groups, word-of-mouth knowledge dominates (Morton, 2008b), and the Amish learn which outsiders they can trust from their neighbors' past experiences. This Amish disinclination to trust "the English" makes sense as a result of the extreme vulnerability of the Amish to exploitation; they are forbidden by their religion to sue negligent doctors for malpractice, or generally to pursue legal options (Kraybill, 2003). The model of Amish community health clinics arose to meet this community need and provide a place for warm physicians to earn the confidence and respect of the Amish.

Still, the Amish continue to seek out supplemental alternative-medicine treatments, particularly visits to chiropractors, because chiropractors "spend more time talking with their patients and also provide more body contact," explains Hostetler (1993). The Amish also often visit reflexologists, herbalists, "quack" doctors who dispense vitamins (Morton, 2008b), and baruche practitioners. Baruche, or sympathy-curing, is generally practiced for free by Amish elders and consists of continually repeating verses of a charm. However, today baruche is not universally accepted within the Amish community (Hostetler, 1993).

Amish dependence on alternative medicine reflects this need for warm human connection and enduring, unhurried interactions between patients and practitioners and researchers; this allows the Amish to overcome their natural distrust of outsiders and form strong bonds with medical practitioners.

### THE AMISH COMMUNITY HEALTH CENTERS

In 1990, a Harvard-trained pediatrician, Dr. Holmes Morton, established the first Amish community health center, named the Clinic for Special Children. The clinic serves as a nonprofit medical and translational research center in Lancaster County. Translational research aims to integrate clinical medicine and basic laboratory science to improve patient care (Belkin, 2005). The clinic seeks to provide the Amish with empathetic, long-term medical care that also gives them a sense of agency—neither of which is possible in the medical genetic tourist model. In a 1994 interview, Dr. Morton explained:

I know that studies of the genetic diseases of the Amish and Mennonite people have provided important knowledge, but I also know that some of the work with the Amish and Mennonite people of Lancaster County done by teams of people from universities has amounted to

little more than medical tourism. Too often these teams of physicians, students, and blood drawers were disinterested in the health care needs of those whose genetic diseases were studied. This is a harsh judgment, but it is true, and the Plain People [the Amish and Mennonites] know this. (Hendricks, 1994)

Dr. Morton's dedication to the individual patient's health, as well as to primary care as a means of discovering interesting new research projects, represents a distinct break from the previous tradition of genetic tourist scientific inquiry. His commitment to treating patients around the clock, working nights and weekends and making house calls, has earned him the community's trust over time. "The only reason they have any trust in me is that I go out and see them in the middle of the night. They know the clinic is not a trailer that I'm going to haul away," notes Morton (Hendricks, 1994).

Dr. Morton's introduction to the Amish community began during his tenure as a research fellow in metabolic diseases at Children's Hospital of Philadelphia in 1998, when he came across GA1. At the time, there was little medical literature on GA1, sparking Morton's interest and his first visit to Lancaster County, where he would soon find many more cases of GA1, which had been mistakenly labeled cerebral palsy. There, Dr. Morton soon became convinced of the need to open a nonprofit medical clinic in Lancaster County for the treatment of GA1 and other Amish genetic disorders. Through Dr. Morton's special dietary formulations (which control protein levels) suited for children with GA1, as well as his emphasis on early GA1 diagnosis, he was able to decrease significantly the number of Amish GA1 babies suffering permanent neurological injury. When Dr. Morton arrived in Lancaster County, 95 percent of GA1 children had permanent brain damage (Belkin, 2005); Morton's work resulted in that figure dropping to only 25 percent of GA1 children by 2006.

Morton's early track record with his GA1 patients helped him achieve his goal of opening the clinic in 1990. Notably, the land the clinic was constructed on was donated by an Amish farmer, Jacob Stoltzfoos (Morton, 2008b), who had a grandchild who had been an early GA1 patient of Morton's. And it was the Amish community's support, trust, and appreciation that made the physical construction of the clinic possible—via a traditional community barn-raising. The *Wall Street Journal* reporter Frank Allen recounts:

Shortly after dawn on Saturday, 10 Amish carpenters arrived at a pasture flanked by leafless sycamore and maples. . . . Soon 50 more men were there, most of them Amish and Mennonite farmers. They had been delayed by morning milking chores, but they were eager to help with the day's unusual project: They had come as volunteers in a barn-raising, actually a "clinic-raising," to help the children of this community who suffer life-threatening genetic disorders (Allen, 1990).

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The collective construction of the clinic demonstrates the agency afforded the Amish in their own medical care and in scientific research studies by the Clinic for Special Children. This openness and shared responsibility directly contrast with the legacy of paternalistic medical genetic tourist forays. The deeply felt Amish community trust in Dr. Morton, which facilitated the establishment of his research program, was simply not possible for visiting genetic tourists; for them, the first priority is yielding solid, publishable results for their research studies, rather than looking out for the health and well-being of the entire community. In contrast, the clinic setup results in more-tangible benefits for the Amish community; it provides them with medical care that is more affordable, personalized, and sympathetic than that available at local hospitals. For example, the Clinic for Special Children charges only \$35 per patient visit.

Such patient fees make up 20 percent of the clinic's budget, while another 30 percent comes from several fundraising auctions organized by patient families throughout the year. The remaining half of the budget comes from nonprofit donations (Morton, 2008a). Thus, the clinic is relatively financially dependent on the Amish, which guarantees them influence and bargaining power in determining research priorities.

While the Amish community was central in the establishment of the Clinic for Special Children, Allen's series of sympathetic articles on the clinic, notably one about its financial troubles, spurred several large charitable donations—including lab equipment from Hewlett-Packard and more than \$200,000 from private donors—which made the clinic's establishment financially feasible (Allen, 1990).

This account of the clinic's founding highlights how Dr. Morton used his role as a primary care physician treating individual patients in order to win the trust of the Amish community—enabling his later intensive, scientific translational research program at the clinic. Today at the clinic the same samples used for diagnostic tests on Amish patients and their families are later used for research studies, as patients sign release forms allowing their DNA to be used for further research. This has resulted in the clinic having thousands of samples stored in its freezers available for medical genetic research studies. Moreover, in recent years the clinic has expanded from having Dr. Morton as its sole medical practitioner. Today the clinic has two physicians—Dr. Morton and pediatrician Dr. Kevin Strauss, as well as scientific researcher Dr. Erik Puffenberger, who holds a PhD in human genetics and runs the clinic's laboratory. Dr. Puffenberger works with the physicians to conduct translational research, as well as to carry out routine diagnostic tests for patients in the lab (Puffenberger, 2008). This team has made several medical breakthroughs, including the characterization of a new genetic disorder called pretzel syndrome (associated with brain malformation and seizures)

(Puffenberger et al., 2007), as well as the discovery that liver transplants cure a metabolic disorder called maple syrup urine disease (a disorder in which patients cannot break down certain amino acids, such as leucine) (Strauss et al., 2006). Furthermore, the Clinic for Special Children discovered and first described a condition called Amish lethal microcephaly, which is an autosomal recessive genetic disorder resulting in a small, malformed brain and death before age one (Kelley et al., 2002). All of these breakthroughs were possible only as a result of the clinic's long-term medical care of its Amish patients, allowing its physician-scientists to observe at first hand the natural history of these genetic disorders and their occurrence within Amish families. In the words of former U.S. Surgeon General Everett Koop, "Holmes Morton has forced his way into the hearts of the Amish people and, based on that trust, has accomplished a remarkable service" (Ulrich, 1997).

The Amish community's gratitude toward Dr. Morton and the clinic staff is evidenced by the strong bonds clinic patients and their families often form with the "English" clinic staff, despite the culture gap. One Amish family, whose son had CHH dwarfism and SCID (severe combined immune deficiency), became particularly close to the staff during the course of his treatment. Since the son's passing several years ago, the family has invited the entire clinic staff to its home every year for dinner.

Another Amish clinic was established in May 2002 in Geauga County, OH. The Ohio clinic, called the DDC (Das Deutsch Center) Clinic for Special Needs Children, was modeled after Dr. Morton's Clinic for Special Children in its financial structure, Amish community involvement, commitment to primary care medical practice, and groundbreaking medical genetic research program. The Ohio clinic was first proposed by a group of Ohio Amish women with special-needs children. These women had read an article about Dr. Morton's Clinic for Special Children in the *Reader's Digest* ("About DDC," 2009). After visiting Dr. Morton's clinic for two days without receiving definitive diagnoses for their sick children, the Ohio Amish families returned home. However, the Ohio clinic's website explains,

They [the Amish families] immediately set their sights on developing a clinic in Northeast Ohio that could assist their families in a similar way. They solicited organizational support, visited Dr. Morton's clinic, gathered information, researched all aspects of the clinic, developed a board of trustees, and applied for non-profit status. Dr. Heng Wang [MD, PhD] was hired as the Medical Director. ("About DDC," 2009)

The Ohio clinic, like Dr. Morton's clinic, relies financially on proceeds from fundraising auctions as well as on charitable gifts from foundations and wealthy individuals. And Amish religious leaders were also integrally involved in the Ohio clinic's establishment. The 72 local Amish

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bishops in Ohio “blessed the appeal to modern science as in tune with their practical traditions. In the last two years, they raised \$700,000 from the faithful—farmers and factory workers—towards the \$1.8 million center,” reports the *New York Times* (Clines, 2002).

Today the Ohio clinic treats patients with more than 37 different genetic disorders. These disorders are largely distinct from the disorders found in the Lancaster County Amish, as the Lancaster County and Ohio Amish were founded by different individuals, with different genetic makeups (though they all hailed originally from similar geographical areas) (“About DDC,” 2009). Over the past few years, the Ohio clinic has made a number of medical breakthroughs; these include characterizing a never-before-seen disease called ganglioside GM3 synthase deficiency, which the Ohio clinic’s Dr. Wang described in a research paper published in the journal *Nature Genetics*. This disease, which is autosomal recessive, causes severe epilepsy and is associated with blindness and developmental delay. Soon after Dr. Wang’s paper was published, several other children throughout the country were diagnosed with ganglioside GM3 synthase deficiency (“Research Update,” 2005).

## CONCLUSION

The breakthroughs achieved by both the Clinic for Special Children in Pennsylvania and the DDC Clinic for Special Needs Children in Ohio illustrate the success of the medical genetic research program as conducted via the community health clinic model. These clinics, designed to meet the unique cultural and economic realities of the Amish, signal a stark transformation from the earlier medical genetic tourism. Whereas medical genetic tourism was characterized by paternalism, the clinics herald a new sense of collaboration between medical researchers and the Amish population. This collaboration is facilitated by the warmth and empathy exhibited by the clinics’ staff physicians, who make primary care for the individual patient a priority. In addition, Amish financial support for the clinics gives the Amish community a sense of agency in determining the research agenda. While such collaboration with the Amish community aided the early efforts of Dr. Morton in Pennsylvania, in Ohio it was the Amish themselves who founded, planned, organized, and made possible the Ohio clinic from the start. This illustrates just how much the clinic model has achieved in making science and high-tech medicine more accessible and palatable to the Amish.

Just as the Amish are viewed as an exemplar of morality by many, the success of the clinics is a paradigm for how medical genetic research can be sensitive to the needs of unique minority communities in the United States. Such sensitivity is crucial given the bright promise of personalized genomic medicine for the future of American healthcare.

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