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"Is Being Short A Disability?" Examining How Disease and Disability Have Framed the Medical Treatment of Short Stature

Abstract: This article aims to contribute to the subfield of disability in the history of medicine by demonstrating how an axiomatic understanding of ability operates in medicine and how disability provides an interpretation for difference and a materiality to pathology. Indeed, disability often serves as a therapeutic challenge in medicine, even while it documents its curative limits and complicated relationship with the state and health-care system. Using the history of the human growth hormone industry in the U.S. as an example, it illustrates how, since the 1960s, claiming disability has legitimized the medical treatment of short-statured children by garnering public support and justifying therapy. It also shows how debates around its treatment often play out on the murky boundary of disease and disability. In doing so, this article examines ability as an enunciative modality in medicine and the historical construction of claiming disability, a multifaceted contingent process that incessantly changes over time.

In 2006, a *USA Today* article ran with the headline: "The debate is growing: Is being short a disability?" (Rubin 6D). In order to demonstrate the difficulties children of short stature faced, journalist Rita Rubin began her article by sharing with readers a beginning-of-the-school-year to-do list from parents of a son with short stature. The parents' list from some years ago addressed the needs of their son Spencer, who was starting kindergarten at the time and included items such as "get backpack" and "check height of school toilets" (Rubin 6D). According to Rubin, the parents feared the facilities in the school restrooms would mirror those in other public places and their son Spencer, due to his height, would be unable to access the toilets without assistance. Their anxiety subsided after a bathroom check revealed the toilets were smaller-than-average.

The article continued to document the trials and tribulations the Davies family experienced due to Spencer's short stature, which included strangers commenting on his height without provocation. It got so bad, according to Rubin, that the parents placed their son on human growth hormone (HGH) when he was 6 and ½ years old, even though clinical tests had not determined an organic cause for his short stature. At first, the family's insurance would not cover the treatment because Spencer's short stature could not be linked to a growth hormone deficiency and was not technically considered a disability requiring medical therapy, but this decision was reversed after an outside review board ruled in the family's favor.

Later in the article, the journalist reported on the success of Spencer's therapy by using cultural indicators of success: he was 4 foot 1 at age 11, a straight-A student and a top-ranked wrestler (Rubin 6D). The continuous social and physical struggles Spencer faced, the family's long fight in getting their insurance to cover his therapy, and the journalist's selection of benchmarks used to document successful medical treatment speak to how both short stature and disability are understood in our society.[1] Short stature is seen as a shortcoming, even in children, and disability works as an administrative category, which can open the door to financial assistance, even after it has been slammed shut by an insurance agency.

The parents' decision to claim a disability identity for their son no doubt came from the high cost of human growth hormone therapy. Treatment involves a series of daily shots of HGH given over several years. A month's supply could cost anywhere between two to five thousand dollars. On average, children like Spencer (diagnosed with Idiopathic Short Stature or ISS) can expect to take human growth hormone for at least 5.3 years in order to gain 1.6-2.4 inches in adult height (Cuttler and Silvers 2004, 108). Based on these calculations, denied coverage would have cost Spencer's parents anywhere between $125,000 to $300,000 (Cuttler and Silvers 2010, 3154).

The fact that the Davies won their long fight against an insurance company is important. Even after the Food and Drug Administration approved the use of HGH for ISS in 2003, the top four health insurers in the U.S.– UnitedHealth Group, Kaiser Foundation Group, Wellpoint Inc. Group, Aetna Group—do not consider it a disease nor a functionally-limiting-impairment, and many plans exclude coverage for short stature not caused by "a diagnosed medical condition" (Heilbrunn, "Top Health Insurance Companies"; Aetna, "Growth Hormone"; UnitedHealth Group, Growth Hormone; Kaiser Permanente 6; Anthem, "Position Statement"). In fact, the Human Growth Foundation, an organization that has facilitated human growth hormone therapy in the U.S. for over fifty years, features on its website a "mini primer" on how to prepare an appeal of denial of insurance coverage, stating that if an appeal is unable to substantiate growth hormone deficiency (GHD) as the cause for short stature then it will likely be denied (Gershenhow 1).

While the *USA Today* article did not go into specifics of the appeal, perhaps the lawyer for Spencer's parents tried to meet the Social Security Administration's (SSA) definition of disability for children. The SSA asserts that in order for a child to be eligible for supplemental security-income disability benefits, he/she must have "a physical or mental condition(s) that very seriously limits his or her activities; and the condition(s) must have lasted, or be expected to last, at least 1 year or result in death" (U.S. Social Security Administration, "Child Starter Kit"). With Spencer's diagnosis of ISS, the lawyer would have had a difficult time meeting the criteria set forth by this definition. While the SSA identifies growth impairment in childhood as sometimes debilitating and/or a symptom of an undiagnosed disease; it does not consider short stature itself as "a medically determinable impairment" (U.S. Social Security Administration, "DI 24598.001"). Furthermore, when familial short stature can be established, as was possible in Spencer's case since both of his parents were short, then short stature is understood neither as impairment nor as a sign of an undiagnosed disease (Rubin; U.S. Social Security Administration, "DI 24598.001").

Even though Spencer's disability status might not have met the SSA's standard, it did connect him to a modern civil rights movement stretching back decades. With its attention to gaining access, securing accommodations, and combatting social prejudices, the disability rights movement (too complex to cover here in detail) has successfully championed the rights of those with complex embodiment since the 1960s. Its legal victories include the Rehabilitation Act of 1973 (protects qualified individuals with disabilities from discrimination), the Education for All Handicapped Children Act of 1975 (guarantees equal access to education), and the Americans with Disabilities Act of 1990 (prohibits discrimination based on disability) (Fleischer and Zames, 49-55, xxiv). Even with these accomplishments, the disability rights movement and its population are still found primarily on the margins of society and do not appear to be to have been in the purview of the *USA Today*'s journalist who was considering the disability status of short stature. Instead of invoking the heroic stories of pioneers

from this movement or examining its critique on the persistent discrimination people with disabilities face, Rita Rubin suggested the more common tragic story of disability in order to provide a litmus test to the magnitude of the hardships endured due to short stature and an investigation into the curative properties of HGH (Rubin 6D). In doing so, Rubin spoke from a medical understanding of disability, something disability activists have also fought against but with less success. Activists maintain that medicine's obsession with the normal and the individual motivates it to fix natural variation and has fueled the discrimination and bias treatment of those deemed different (Kudlick 770-773).

Because they were willing to alter their son in order to fit into society and meet structural norms, the Davies might be seen as hoodwinked by the medical model of disability. And yet this allegation of false consciousness overlooks the way in which they harnessed disability's power in order to insure health care for their son and the historical construction of claiming disability more generally. In Spencer's case, disability transformed a short kid with short parents and a somewhat ambiguous medical condition (ISS) into a worthy recipient of an expensive treatment that his family could not afford without the help of its health provider.

The act of claiming disability operates in various compensatory venues as a catalyst for access, especially when other efforts have failed. Anthropologist Kelly Knight has documented how changes in the welfare entitlement structure during the mid-1990s profoundly affected how and why poor, pregnant addicts of daily-rent hotels in San Francisco made decisions about claiming disability. In 1996, the U.S. Congress passed the Contract with America Advancement Act. This Act included the decision no longer to allow individuals who claim drug and alcohol dependence as their primary disabling diagnosis access to Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). So those in need had to search for and identify with additional disabling diagnoses in order to keep up their moral standing and benefits. This is no easy task, and as Knight argues, the policy changes ultimately gave birth to the neurocrat. This person guides women through this new bureaucratic layer of welfare and collects convincing evidence of a disabling serious mental illness that is able to legitimize their need for help.[2] Subsequently, in the wide bureaucratic webs of health care and governmental assistance, disability as an administrative category connects what appear to be on the surface disparate constituencies—short boys and pregnant drug addicts—and transforms them into respectable recipients of care. In both cases, it is the medical understanding of disability that proves to be powerful enough to validate care as it strips them of their personal agency and transforms them into innocent victims of their bodies and minds.

Hence, disability functions in the framing of disease, especially when the understanding of the perils of disease and deformity are made most lucid by it. Even so, scholars often overlook the enunciative relationship between disability and disease. Historian of medicine Beth Linker's 2013 article "On the Borderland of Medical and Disability History: A Survey of the Fields" offers a series of reasons as to why this is the case and includes the process of professionalization as one of them. According to Linker, historians of medicine have adopted a scientific lexicon when describing health and disease in order to gain acceptance by the very field they write about: medicine. Focused on the molecular over the body, the cause over the symptom, and the laboratory over the environment, scientific medicine prefers a disease-focused approach to knowledge-making. Diseases are defined, well-contained, discernible biological events, while disabilities are ambiguous, subjective, and interpretive utterances. As Linker suggests, "within the history of medicine, we have an abundance of

disease (including pharmaceutical) histories that cover smallpox, tuberculosis, and cardiovascular disease, but few—if any—accounts that look at these conditions from a disability perspective" (505). But what does it mean to take on a "disability perspective" as a historian of medicine?

For disability historians, writing with this perspective has meant documenting the history of people with disabilities and defining disability as an identity and not a life sentence of suffering. While disability historians' contributions to recovering the past are too many to be named here, their social-minority approach to doing history serves as a meaningful reminder as to the power of the motivation to recover one's own history.[3] Most disability historians have examined the past with the purpose of pointing out how social discrimination has been the cause of most of the suffering people with disabilities have endured and how medicine has often justified or perpetrated this poor, often inhumane, treatment.[4] In doing so, these scholars refuse the medical model of understanding disability and deemphasize links between diseases and disabilities.[5] Hence, disability historians have shied away from investigating how disability operates and garners power within medicine.[6]

With disability historians hesitant to discuss any correlation between disability and disease and historians of medicine writing about disease history with a scientific-medical lexicon, the interplay between disability and disease has been obscured. This article aims to contribute to the subfield of disability in the history of medicine by demonstrating how an axiomatic understanding of ability operates in medicine and how disability provides an interpretation for difference and a materiality to pathology. Indeed, disability often serves as a therapeutic challenge in medicine even while it documents its curative limits and complicated relationship with the state and health-care system. Using the history of the human growth hormone industry in the U.S. as an example, I plan to illustrate how, since the 1960s, disability has legitimized the medical treatment of short-statured children by garnering public support and justifying therapy. I also plan to show how debates around its treatment often play out on the murky boundary of disease and disability. In doing so, this investigation is not predicated on the discovery of a marginalized people; rather, it is an examination of ability as an enunciative modality in medicine and the historical construction of claiming disability, a multifaceted contingent process that incessantly changes over time.

Public Service Announcements, Growth Hormone, and Disabling Short Stature

"Hellish dwarfism," "painful life," "bombarded with taunts"—depicting the disabling nature of short stature has been a staple of human-interest stories intended to serve as public service announcements to raise awareness around human growth hormone therapy since the 1960s (Shearer 6; Steinbrook A1). The desire to inform the public about this medical treatment in large part had to do with a new need to locate a growth hormone that could be made available for future use. While GH treatment for short children dates back to the 1920s, the source of the hormone had shifted from animal to human in the late 1950s when scientists discovered that the hormone is species-specific. Starting then, growth hormone treatment comprised human growth hormone shots, and the hormone solution was the product of HGH that had been extracted from the pituitary glands of dead people. During the era of cadaver human-growth hormone (cHGH) therapy, clinical-grade cadaver human growth hormone was highly sought after and stories about puny white boys who had been responsive to therapy when it was made available to them served as pleas to the public to donate one's pituitary gland to the cause.

Take for example an article that ran as the lead story of the *Parade* magazine of *The San Diego Union* on August 22, 1965. The cover of this newspaper section featured a smiling white boy with the tagline "THIS BOY IS A DWARF" and a declaration in its banner claiming "WE CAN END DWARFISM!" (Shearer, cover). The journalist Lloyd Shearer reported on this boy, Harold Riley, as one of the lucky "little people" being "treated with human growth hormone" (5). A junior in high school, Harold had "top grade" health and intelligence but was only 4-feet-5, even after he had grown more than five inches in the last two years due to the "miracle hormone" (5).

According to the article, Harold's treatment began after his mother first noticed his clothing size had not changed in years and took him to physician after physician, until a pediatrician finally diagnosed him with a growth hormone deficiency. The pediatrician referred Harold to a doctor who had a friend who worked at the National Institutes of Health (NIH). The insider was able to connect the Riley family with a medical expert receiving human growth hormone for clinical research from the NIH-affiliated National Pituitary Agency (the NPA ran the collection, processing, and distribution of cHGH in North America from 1963 to 1985). Once treatment began, Harold experienced a two-year growth spurt.

Shearer reported how an avoidable limited supply of cHGH had hindered the treatment of dwarfed children like Harold as he argued that better access to the bountiful supply of this hormone could cure the estimated 10,000 children in the U.S. whose "height-shortage was caused by a dysfunction of the pituitary gland" (5-6). Instead, therapy often experienced a series of abrupt stops due to unnecessary cHGH shortages, as was the case for Harold. Mrs. Riley's frustration over the sporadic supply was included in the article. She stated, "if we can just get a steady supply of it, he stands a very good chance of growing another 8, 10, maybe 12 inches. Whenever I get a supply from the agency, I give him the shot myself . . . Harold is so close to making 5 feet, I just know he will. There's nothing I wouldn't do to normalize his life" (6).

This article gave readers hope and advice on how they too could help these needy children by willing their pituitary glands and inspiring friends and relatives to donate their glands to the National Pituitary Agency. Readers were also encouraged to volunteer to work with pathologists in their local neighborhood hospitals to contribute pituitary glands. The need was great, as the supply remained inaccessible because of people's failure to donate. The article pointed out that approximately 1,500,000 people had died in 1964, yet only 50,000 pituitaries were collected. Shearer pleaded with his readers to donate by stating, "if you can, won't you please help, especially before it's too late, and the bones of some undersized boy or girl have fused, forcing the poor child into a life of hellish dwarfism?" (6). If damnation wasn't enough, Shearer also tried to encourage donations by reporting on the "waves of anger, pain, and supersensitivity of a child who is not like other children" and the hardships of being small (5).

In order to campaign for more pituitary glands throughout the 1960s and 1970s, press supporting cadaver human growth hormone therapy evoked disability as a compelling argument for care. Reports depicted sufferers (mostly boys) of short stature who were facing a life of doom if they were unable to seek treatment (Alvarez; "Children with Growth Ills"; "Helping the Little People"; Steinbrook). For example, in a 1966 *Los Angeles Times* article, journalist Walter Alvarez reported on the horrors of short stature and how "obviously, a lad who is only 4 feet tall is going to be terribly handicapped and unhappy for the rest of his life, and hence everything possible should be done to make him grow as he should" (D12). Sometimes the disabling nature of short stature was understood as more immediate, as in the case of 14-year-old Erick Carstensen. His story

was featured in a May 7, 1973 *Time* magazine article titled "Helping the Little People." The article reported how this 14-year-old felt alienated by other students who excluded him from games and by teachers who mockingly called him "shorty" and harassed "him for his inability to keep up with his classmates in physical education" (106). Short stature was also depicted as a perpetual disability, as in a 1978 *Chicago Tribune* article "Hormone Means Life is Looking Up for Short People." Journalist Robert Steinbrook evoked name-calling by using the impersonal catch-all term "shorty" to speak of those who were agonized by their stature. He elaborated on their hardships by reporting, "at school he is bombarded with taunts of shrimp, small fry, midget, and dwarf" (A1). He also predicted their bleak futures by suggesting that, instead of happy lives, each of them will lead "a painful life as a loner, fraught with incredible anxieties about sex and success at work or school" (A1). These stories were intended to convey to readers how terrible it was to be short and how medicine was able to correct this disability, when linked to growth hormone deficiency, if only given the opportunity.

Holding up GHD boys as poster children for growth hormone therapy, these reports quantified their cure in vertical inches, which contributed to the understanding that short stature was a disability that could be corrected through added height. In short, growth hormone therapy worked because it enabled boys to grow taller. Just as in Spencer's case, more height meant increased happiness, improvement at school, and normalcy for these boys. For example, in journalist Carolyn Lewis' 1966 article, "Their Hope Grows by the Yardstick," Lewis conveyed the benefits of growth hormone therapy by interviewing a father of a boy in treatment. This father reported on his son's progress by stating, "[h]is face just lights up whenever he learns he has grown an eighth of an inch" (F5).

The power of height was also invoked in the disability narrative of Virgil Anderson Jr., a young man who received cHGH therapy under the care of Dr. Willard Vanderlaan, head of the Division of Endocrinology at Scripps Clinic of La Jolla in San Diego, California. Before treatment, Virgil, was 4 feet 4 at age 15, was taunted by his peers and adults, was called nicknames like "shorty," and "was pretty unhappy with himself" (Bowler, A23). During therapy, Virgil grew eleven inches, and by age 22, his life had changed because he was bigger, so it was argued. As journalist Leo Bowler suggested, at 5 feet 3, Virgil was "a happy, productive man" as he worked alongside his father as an operator of an aluminum shingle-manufacturing machine (A23). According to reports, Virgil owed his joy and success to the cHGH he received at Scripps Clinic with one journalist quoting Virgil as saying "I would never have been able to make anything of myself without Dr. VanderLaan's help" (Lewis, F5).

Instead of exposing the flaws in cultural perceptions of height, the media reporting on growth hormone therapy referred to cHGH recipients as the lucky ones because they had a treatable form of short stature and were able to overcome discrimination through the donation of others. While these anecdotal stories of tragedy and promise promoted the medical correction of the body in the name of social acceptance and peace of mind, child psychologists were busy investigating the psycho-social impact of being small. Their research focused on children and adolescents and moved short stature's etiology further away from disease and closer to disability.

Psychologists Weigh In

Psychologists' body of work examining the disabling nature of short stature began to grow in the 1960s in parallel to the

development of effective human growth hormone therapy. Sometimes these two scientific endeavors directly inspired one another, as was the case at Johns Hopkins University. There, Ernesto Pollitt and John Money saw the new pediatric growth study at the hospital (which included cHGH therapy) as an opportunity to conduct a longitudinal psychological study of small-statured children. In 1964, they began publishing their findings about the psycho-social impact of short stature in order to later assess whether "physical benefits from growth treatment" corrected character flaws that were linked to their height (Pollitt and Money 1964, 421). Based on their observations of seventeen children, they reported that small stature was indeed a disability. Pollitt and Money argued that it negatively affected school performance, interpersonal relationships, and overall personality and that all of these hardships were interrelated (Pollitt and Money 415, Money and Pollitt 389). For example, the short children they studied seemed to be more interested in social acceptance than academic performance and their quest to fit in interfered with their schoolwork (Money and Pollitt 388). They also suggested that short stature compromised relationships between child and parent, especially when the parent babied the child. In turn, the child's "psychomaturation" was often delayed and "personality disturbances" grew out of this dysfunctional relationship (Money and Pollitt 386). Their findings went on to frame subsequent scholarship as researchers drew similar conclusions when it came to short stature's impact on "social competence, behavioral problems, self-esteem, and family functioning" (Gordon, Crouthamel, Post, Richman 477; Stabler and Underwood, Slow Grows the Child; Gold).

As evidence mounted indicating the hardships of being short, growth hormone deficiency (GHD) also became an object of study. Throughout the 1970s and 1980s, studies were conducted to examine a possible causal relationship between GHD, personality disorders, and learning disabilities. One study conducted by H.C. Steinhausen and N. Stahnke of Children's Hospital at the University of Hamburg, West Germany, aimed to tease out the endocrinological component from negative personality traits they witnessed in small children and adolescents. Steinhausen and Stahnke assessed that these children were "less aggressive," "less excitable," "less conscientious," "more tender-minded," and "less shrewd" than their normal peers (780). Upon further investigation, these scientists concluded that these character flaws were due to the children's stature and not GHD. It was their scientific opinion that the disability, short stature, not the disease, GHD, was the medical problem (782).

In fact, some studies demonstrated that short stature with no pathological origin was the most debilitating of all. In a September 1982 *Journal of Pediatrics* article, Dr. Michael Gordon, the lead investigator and doctor from the departments of psychiatry and pediatrics at the State University Hospital at the Upstate Medical Center in New York, reported on the study of twenty boys and four girls with constitutional short stature (CSS). The findings suggested that children with CSS had significantly more behavior problems and less self-esteem than a matched control group with normal height and that these findings were in contrast to recent evaluations of children with growth hormone deficiency. Investigators postulated that children with CSS were more frustrated with being short because they did not know why they were short while the GHD children understood the cause of their short stature, received medical care at top-notch universities for it, and remained hopeful that they were going to grow taller (Gordon, Crouthamel, Post, Richman 479-480).

By the mid-1980s, the prevailing view in child psychology and pediatrics was that short stature, regardless of cause, was disabling. As Deborah Young-Hyman of University of Maryland

Medical School remarked in 1986:

> The psychological literature concerning short-statured children is remarkable in that, with few exceptions, the conclusion is that shortness is a handicapping condition. This conclusion has led to an extensive effort by pediatric endocrinologists to seek effective forms of treatment, and has motivated mental health professionals to study these children. (Stabler and Underwood 27)

Even in an article that questioned how detrimental being small was for "short normal children," the hegemonic notion of the disabling nature of short stature was not refuted (Law 855).

Is it Medically Necessary to Treat Short Stature?

During the early 1980s, short normal children became increasingly of interest to researchers as a Food and Drug Administration (FDA) approval of Genentech's biosynthetic human growth hormone product, Protropin, was looming. It was predicted that this change in HGH therapy would be revolutionary. No longer bound to extracted pituitaries, human growth hormone therapy could be made more available because the source of the drug would be laboratories and not morgues. This theoretically limitless supply shifted the debate about treatment because, with enough to go around, anyone who was short could undergo therapy. In 1983, the National Institute of Child Health and Human Development held a conference on the future uses of recombinant DNA human growth hormone. Pediatric endocrinologists, psychologists, bioethicists, representatives from the National Institutes of Health, the FDA, and pharmaceutical companies producing pituitary-derived and biosynthetic human growth hormone convened to discuss the treatment of non-GHD children. The "conferees agreed that severe shortness of stature is not a trivial problem. Rather, for some children and adults it is a psychologically disabling condition" (Underwood 608). Instead of challenging the notion of treating short stature or further investigating their hunch about its disabling nature, they recommended therapeutic trials be conducted in order to see the effectiveness of HGH therapy for short normal children and to determine realistic expectations when it came to treatment. Subsequently, concerns surrounding treating non-GHD short children with HGH were around patient perceptions and not their undergoing therapy.

In 1985, the FDA finally approved Genentech's Protropin after a medical tragedy left clinicians searching for a new supply source. Early that year, cadaver Human Growth Hormone therapy was linked to cases of Creutzfeld-Jakob Disease (CJD), the FDA pulled commercial cHGH from the market, and the NPA halted its human-growth hormone program. With no pituitary-based HGH available, Genentech's Protropin was the only source of therapy from the fall of 1985 until 1987 when Eli Lilly received FDA approval for its recombinant human growth hormone (rHGH) product, Humatrope. By then, Genentech had made millions off of its biologic (Medeiros 191).

As the biotech era of human growth hormone therapy took off, journalists ceased the opportunity to comment on the changing ethical landscape of treating short stature by using the language of ability to caution against the overuse of rHGHs. Some suggested rHGH might be ushering in a "Brave New World" where "cosmetic endocrinology" could enhance a child's quality of life and reported how parents had "already begun to besiege doctors to prescribe the hormone for kids who ultimately will be only slightly shorter than normal or even of average height" (Kolata and Otten 33). Journalist Russell Baker cautioned his readers about rHGH's

potential in his article titled "Think Twice About Growth, Dads and Lads." Baker warned, "[w]ith the powerful growth hormone coming onto the scene, it's anybody's guess what the social effects will be. We are not talking about a few gracefully muscled 7-footers . . . but about hordes of 400-pound giants, people who have had themselves artificially enlarged in hopes of cleaning up financially in athletic careers" (19). Reporters also related stories from pediatric endocrinologists about parents desiring GH therapy for their sons so that they could be super-fit and successful. Pediatric endocrinologist Rebecca Kirkland remarked to a journalist that "[o]ne man said his son would be a better attorney if he was taller" (Kolata 23). Journalists evoked these types of reports from specialists of parents demanding human growth hormone therapy for their short sons as examples of the ruthless nature of using the drug solely to give boys an advantage. For twenty years, media surrounding HGH therapy stressed the need to treat GHD children in order to save them from short stature and now, once the treatment became more theoretically available to any short child, there was a backlash to its potential overuse.

Even though a black market of rHGH grew during the 1980s and 1990s, most pediatric endocrinologists were conservative when prescribing rHGH and only recommended its use in cases where short stature was linked to a disease or biological disorder. A mid-1990s NIH-funded survey of 434 U.S. pediatric endocrinologists indicated that 58% of rHGH patients had GHD. Girls with Turner Syndrome made up the majority of the other 42% and the rest were a hodgepodge of children with various conditions including chronic renal insufficiency, familial short stature, and ISS. It is important to note that even though the majority of children who underwent rHGH therapy were short because of a diagnosed disease or biological dysfunction, treatment targeted their stature and not their disease (Cuttler and Silvers 2005, 3150).

Only prescribing rHGH in cases of short stature due to disease was seriously questioned in 2003 when the FDA's Endocrinologic and Metabolic Drugs Advisory Committee held a meeting to consider approving treating non-growth-hormone-deficient short stature with Eli Lilly's rHGH product Humatrope. Representatives from Eli Lilly, pediatric endocrinologists, and other medical specialists championed its approval by providing a "rationale for treatment," and claiming its efficacy and safety (Department of Health and Human Services 1-19). At the meeting, it was argued by GH expert Raymond Hintz from Stanford University that children who fell below the minus-two standard deviation score in height should not be denied treatment because medicine had failed to link their short stature to a disease. He also noted that in cases of GHD or other FDA-approved conditions for rHGH therapy, short stature and/or growth hormone had been the focus of treatment and not the disease (20-30). His messages reverberated throughout the duration of this meeting.

The Committee also heard testimony advocating for Humatrope's approval in cases of ISS during an Open Public Hearing. Anecdotal stories served as evidence documenting the perils of short stature and the curative promise of human growth hormone therapy. The hearing kicked off with a letter addressed to the committee from the "Short Child Family." It highlighted the personal story of 15-year-old Bradley who experienced a boost of self-esteem once he began rHGH therapy and a parental plea for the FDA not to take this opportunity to grow away from him (183). Next, a letter from the Human Growth Foundation (HGF) was read to the Committee. In it, HGF's executive director, Patricia Costa explained how in cases where physicians were unable to identify a cause for a child's short stature, parents "have dual concerns: their child's short stature, and their child's self-esteem that is plummeting" (188). Costa argued for FDA approval of Humatrope

for these children because it would be nothing short of a life-saver (189).

People also testified in person, as in the case of Deno Andrews. He began his testimony on his knees in order to demonstrate how short he was when he was prescribed cHGH (he would have been two inches shorter than on his knees). Andrews called himself lucky because his smallness was due to GHD, which made him eligible for treatment during the cadaver human growth hormone era of GH therapy. He reported on his tragic pre-cHGH days as a child and the ways in which short stature negatively affected his personality and school performance. Andrews also unequivocally championed FDA approval of Humatrope in cases of ISS (193-203). He concluded his testimony by quoting his mother, the founder of the Magic Foundation for Children's Growth, "Please remember, before you make your decision, that children have only a short time to grow, and a lifetime to live with the results" (203). In the end, presentations delivered by experts and personal testimony prevailed as the FDA granted Eli Lilly approval for Humatrope in cases of ISS (Cuttler and Silvers, 108).

Even with FDA approval for the use of rHGH in cases of ISS, the top four largest insurance companies have remained conservative in their coverage policies regarding human growth hormone therapy (Heilbrunn, "Top Health Insurance Companies"). In defense of refusing to pay for rHGH therapy in cases of ISS, these companies are able to cite recent publications that question its safety, along with the psychological disorders associated with short stature, and the disabling nature of being small. Beginning in the 1990s, this body of research interrogated previous conclusions about short stature's negative impact on quality of life for boys as it was said to promote teasing, hinder participation in competitive sports, prove problematic in heterosexual dating, and obstruct attempts to find future employment (Sandberg, Brook, Campos 832-840; Sandberg, Bukowski, Fung, and Knoll 744-750; Colsman, Sandberg, Allen, and Rossi "Treating Short Stature with Growth Hormone"). What they found was that while some boys were teased and unable to play certain sports, this did not mean they developed psychological disorders. In addition, when it came to the realities of dating and finding employment, short men did not experience the level of discrimination some of the previous studies suggested (Sandberg and Colsman 17-25). They also concluded "no rigorously designed studies provide evidence demonstrating that GH treatment leads to improved psychosocial adaptation in individuals with ISS" (Colsman, Sandberg, Allen, and Rossi, "Treating Short Stature with Growth Hormone"). Along with their findings, these researchers championed therapy for families struggling with accepting a member's short stature and cautioned the use of rHGH in cases of ISS as data were scant as to the long-term health risks that might be associated with this treatment (Colsman, Sandberg, Allen, and Rossi, "Treating Short Stature with Growth Hormone").

With the FDA approval of the use of rHGH in cases of ISS and two competing well-established medical opinions about the disabling nature of short stature and value of rHGH therapy, parents (like the Davies) trying to seek coverage for their short children have a chance in fighting against their private insurer's decision to deny coverage, even after an internal appeal has ruled against them. Today, not only do pharmaceutical companies offer assistance in getting coverage, certain states have bureaus regulating health care plans and overseeing external appeals ("Humatrope, DirectConnect").

In California, disgruntled consumers can file a complaint with the California's Department of Managed Care's Independent Medical Review if they have been denied a health-care service or treatment file. An Independent Medical Review is conducted and then a decision is made as to whether the department will uphold

the health plan's decision or overturn it. Since 2001, out of the 226 cases of rHGH therapy for patients 0-18 filed with the California's IMR, 107 have been overturned. Out of these overturned decisions, 49 patients were diagnosed with ISS as defined by the FDA ("Independent Medical Review Search"). As California's IMR seems more open to approving the treatment of ISS with rHGH and is overturning cases based on a patient's ability to meet the FDA's criteria, correcting short stature remains the target of care and the debate about whether this medical fix is necessary persists with no end in sight.

Conclusion

Disease and disability remain at the core of the discussion around treating short stature with growth hormone. Historically, short stature resulting from growth hormone deficiency has been the focus of treatment. Within this context, disability narratives highlighting the hardships of being small and psychological research substantiating that short stature was indeed a handicap justified and promoted human growth hormone therapy for GHD children. Once HGH reserves became theoretically limitless, the requirement of linking short stature to GHD loosened and physicians, with subsequent FDA approval, began treating it when related to other stunting biological dysfunctions, most notably Turner Syndrome. As treatable short stature fell further away from its original disease etiology, its tether was officially severed in the U.S. by the FDA's approval to treat non-GHD short stature with rHGH.

Whether it is used to treat GHD or ISS, human growth hormone therapy reverses the adverse effects of short stature by promoting height. For this reason, disability frames human growth hormone therapy and attempts to pathologize short stature as ability operates in medicine as an axis of power with its implied premise and preference of normalcy and uniformity.[7] Defining difference within this enunciative modality perpetuates the cultural bias for sameness and similarity and provides an opportunity for pharmaceutical companies to offer medical fixes and elaborate on somatic difference as pathological or at least debilitating. Though short stature is not officially diagnosed as a disability in itself, its medical treatment and people's visceral reaction to it stems from a culture obsessed with sameness, superficial appearances, and able-bodiedness at all ages.

Notes

1. To her credit, Rita Rubin tried to deconstruct the prevailing notion that short stature is a disability but used a disability discourse promulgated by the medical model, which perpetuates a deficiency framework for understanding somatic variation.

2. See Kelly Ray Knight, *addicted.pregnant.poor.*

3. See, for example, Paul Longmore, *Why I Burned My Book and Other Essays on Disability.*

4. See, for example, Susan Burch and Hannah Joyner, *Unspeakable: The Story of Junius Wilson.*

5. For meaningful analyses of this trend in disability scholarship, see Susan Wendell, *The Rejected Body* and Alison Kafer, *Feminist, Queer, Crip.*

6. See Beth Linker.

7. For an elaboration on "the ideology of ability," see Tobin Siebers, *Disability Theory*, 7-11.

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Teratology Transformed: The Environmentalization of the Womb in Mid-Century America

On May 14, 1954, in Cincinnati, the pediatrician Josef Warkany and the embryologist James G. Wilson wrote a letter to roughly twelve scientists seeking to organize a society of researchers interested in the field of teratology. Later that year, they were to expand this select group, and fifty-three people would gather for the first meeting in 1956. In their view, teratology had languished since the early part of the twentieth century, and they were reaching out to fellow researchers to solicit interest in forming a group and annual conference dedicated to "causation, mechanisms, and manifestations of abnormal embryonic development" (Warkany and J. Wilson 1). Included in their list of interested parties were geneticists such as James V. Neel (1915-2000) and Curt Stern (1902-1982), who worked on the human health effects of radiation, along with embryologists, developmental biologists, geneticists, zoologists, and anatomists. In addition to academics, the initial meeting would be attended by representatives of the U.S. Children's Bureau, the National Institute of Neurological Diseases and Blindness, seven physicians affiliated with various hospitals, one representative of the Dupont Institute, and four representatives from the Association for the Aid of Crippled Children (AACC) and the National Association for Retarded Children. Though initially a rather academic and anachronistic professional group, they would be drawn into debates about environmental causes of birth defects and how to avoid toxic harm from pharmaceuticals.