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## **"Loving the Monster: The Elephant Man as Modern Fable"** **Suzannah Biernoff**

### **Abstract:**

This chapter explores the rhetoric and politics of ugliness in commentaries on *The Elephant Man*. When David Lynch's film opened in cinemas in October 1980, Bernard Pomerance's play of the same title was packing theatres in London and New York. Many critics took the opportunity to compare the stage and screen interpretations, noting their different approaches to representing deformity and pondering the contemporary relevance of this Victorian tale of cruelty, exploitation and human resilience. Across this contextual field, Merrick's body is produced as a site of abjection: beyond cure and irredeemably repellent. This disavowal of the disabled/deformed body on stage, screen and page occurs at the very moment (1980) that disfigurement is recognized by the World Health Organization as a social impairment. The final part of the chapter identifies the emergence of a socio-cultural understanding of facial disfigurement in medical, anthropological, and journalistic discussions of "Elephant Man's disease" (at the time a widely used term for the genetic disorder neurofibromatosis) and considers Joseph Merrick's legacy for those living with the condition.

### **"The ugliest man in the world"**

When *The Elephant Man* opened in cinemas in October 1980, Bernard Pomerance's Tony Award-winning play of the same title was filling theatres in London and New York. In Los Angeles for the premiere, John Hurt remembered seeing the movie poster on Sunset strip and lines "right around the cinema." It was a film that had "found its audience" (Hurt). Many critics took the opportunity to compare the stage and screen versions of the story, both inspired by Ashley Montagu's *The Elephant Man: A Study in Human Dignity*. They wrote about the different ways Lynch and Pomerance had approached the portrayal of ugliness and pondered the relevance of this Victorian parable of cruelty and compassion. In the off-Broadway play, Philip Anglim – described in the *Boston Globe* as an actor of "crystalline beauty" – performed without makeup, relying on physical theatre to suggest his character's twisted form (Earley 35). For the film, Hurt endured eight-hour makeup sessions as the sixteen latex sections of the elephant man's face and body were laboriously applied. Both productions revolved around the question of "deformity and its various consequences" (Graham and Oehlschlaeger 2). And both claimed historical veracity, emphasizing that theirs was the "true story" of a man we now know to have been called Joseph Merrick, who was born in Leicester in 1862, and spent the last four years of his life in a room at the London Hospital, where he died in 1890 aged 27.

Christopher De Vore and Eric Bergren, who wrote the screenplay with Lynch, had read the account of the surgeon, Frederick Treves, who discovered Merrick in a makeshift penny theatre or "gaff" opposite the London Hospital. Treves's first impression inspired one of the most memorable scenes in the film:

The showman—speaking as if to a dog—called out harshly: "Stand up!" The thing arose slowly and let the blanket that covered its head and back fall to the ground. There stood revealed the most disgusting specimen of humanity that I have ever seen. In the course of my profession I had come upon lamentable deformities of the face due to injury or disease, as well as mutilations and contortions of the body depending upon like causes; but at no time

had I met with such a degraded or perverted version of a human being as this lone figure displayed. (*Reminiscences* 11-12)

A prominent member of the British medical establishment, Frederick Treves (1853-1923) was credited with performing the first appendectomy in England and saving the life of King Edward VII, for which he received a baronetcy. Trained to see physical difference through a diagnostic lens, to chart, compare, explain, and (if possible) treat deviations from the anatomical norm, he approached Merrick first as a specimen, then as an unfortunate victim of fate and circumstance, and finally as a kind of muse. His account is usually read (and these days mostly critiqued) as biography, but its influence transcends questions of historical accuracy. Treves's legacy can be felt in the language of ugliness that eddies through all of the subsequent retellings of the story, and in the conviction that a monstrous body can conceal a beautiful soul.

Published shortly before Treves's death, *The Elephant Man and Other Reminiscences* entered the shadowland of antiquarian bookshops and back-catalogues, where it remained until Ashley Montagu reprinted the title chapter in his book. Although he had come across the story as a teenager in 1923, it was not until the 1940s that he finally tracked down a copy. In the preface to the 1979 edition of his book, Montagu reflects on his enduring fascination with the story (xiii). There is, Graham and Oehlschlaeger observe in their monograph on Merrick's many interpreters, something about the narrative "that recurs or remains" (64). Or perhaps it is the image of Merrick that stays because his is a superlative ugliness, not a flaw or imperfection that might be artfully concealed or surgically corrected. As Kurt Loder says in his *Rolling Stone* review of the Broadway play, "ninety years after his death, John Merrick, the reviled and celebrated Elephant Man, still exerts a magnetic repugnance" (9). Although there have been several stabs at retrospective diagnosis, the condition Merrick suffered from has remained stubbornly elusive. He stands alone, one of a kind. Mel Brooks, whose Crossbow Productions backed the film, called him "the ugliest man in the world" (Mann W31). Since Montagu's book there have been biographies, histories, dramatic interpretations, Kenneth Sherman's volume of poetry, at least four television documentaries,<sup>1</sup> and a host of lovingly crafted elephant men on the online marketplace Etsy.

Even before Lynch's film was released, the elephant man was "big business" ("Return of the Elephant Man" 25). Reviewing the Lyttleton production in London, with David Schofield in the title role, the *Times* theatre critic Ned Chaillet remarked that "there is a cult industry underway" (11). By the time the movie reached cinemas in the fall, Faber's book of the play had become a bestseller, and at least three other versions, by Thomas Gibbons, William Turner and Roy Faudree, had been performed on stage (Graham and Oehlschlaeger 119-34). Treves's "The Elephant Man" had been republished twice more: as the final chapter of Frederick Drimmer's *Very Special People: The Struggles, Loves and Triumphs of Human Oddities* (379-404) and in a 1980 Virgin Books edition of the *Reminiscences*. *The Elephant Man: The Book of the Film* was being promoted as an illustrated souvenir and a novelization of the screenplay by Christine Sparks could be purchased in cinemas. Proprietors were encouraged to contact their local Ballantine representative (the US publisher), who would supply "special displays" featuring the book alongside stills and posters (*Paramount Press Book*).

Before the year was out, Michael Howell and Peter Ford's *True History of the Elephant Man* had cast doubt on some of Treves's biographical facts, including Merrick's given name, and prompted E. S. Turner to ask in *New Society*: "Ought we to be reading another book about the Elephant Man?" (26). The final addition to the bookshops was *The Elephant Man and Other Freaks*, edited by Sean Richards, which Richard Altick called "a wretched paperback" in the *London Review of Books*. "Once again," Altick remarked, "the showmen and the hucksters . . . have been true to the long tradition of the

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<sup>1</sup> *The True Story of The Elephant Man* (1997), *The Curse of the Elephant Man* (2003), *Behind the Shadow of Merrick* (2008), and *Meet the Elephant Man* (2011).

London exhibition trade,” generating “additional revenue from a popular freakish attraction by producing and hawking descriptive pamphlets, ballads, prints, and ‘autobiographies.’” This chapter attempts to explain Merrick’s revival in the 1970s and his enduring fascination, by focusing on two questions raised by contemporary viewers: What does “elephant fever” tell us about modern America circa 1980, and how did the phenomenon affect the way neurofibromatosis (and disfigurement more generally) was understood?<sup>2</sup>

Approaching the elephant man as a cultural phenomenon, rather than as a single text, comes with obvious challenges, not least of all the fact that John/Joseph Merrick is not one person: He inhabits the cultural field a kaleidoscope of images, personas and guises. The adjective that dominates this field is “deformed,” though it usually appears with adverbial embellishment. Merrick’s body is hideously deformed. Horribly deformed. Grossly deformed. Monstrously deformed. Sometimes he is “pathetically” or “grotesquely” disfigured (Siskel, “Hurt Shines” A3), a “medical oddity” (Blau D25, “‘Elephant Man’ Film not from B’way Hit” 52), a “human mistake” (Turner 26) or “human horror” (Wilkie and Rabson 328). Two *Los Angeles Times* reviews, in July and September 1980, quote the passage from Treves’s *Reminiscences*: “There stood revealed the most disgusting specimen of humanity that I have ever seen” (Birnkranz R4, Champlin T34). Phrases from the *Reminiscences* reappear in subsequent retellings of the story, so that one has the impression that Merrick’s body is being ritually called forth as a site of abjection: incurable, abused, exploited, censored, hidden. But it is also a source of hope and consolation because, in the end, Treves’s story is a familiar and reassuring one, “the poignant tale of an outcast who finds a home” (Bayles 68). It is a story in which disgust and sympathy are two opposing poles, and our task is to navigate between them. For anyone who has a passing acquaintance with Christian beliefs, these ideas will sound familiar, not just because of Merrick’s Christ-like acceptance of the cross he must bear, but because the story is pervaded by an understanding of human nature, body and soul, as tragically riven in two. “As a specimen of humanity,” Treves concludes, “Merrick was ignoble and repulsive; but the spirit of Merrick, if it could be seen in the form of the living, would assume the figure of an upstanding and heroic man, smooth browed and clean of limb, and with eyes that flashed undaunted courage” (*Reminiscences* 51). Frail and disfigured, Merrick’s mortal body is the symbolic Other of a radiant, immortal soul. Poets, painters, and playwrights have drawn inspiration from these ideas for centuries, but Christian dualism takes on new and potentially troubling connotations in the context of disability rights, a movement that was gathering momentum as film and theater critics pondered the right and wrong ways of representing Merrick’s deformity. Although the 1964 Civil Rights Act had prohibited discrimination on the basis of race, religion, national origin, or gender, it was not until 1990 that the Americans with Disabilities Act (ADA) extended that legal protection to people with disabilities. The 1970s saw real progress in terms of the growing acceptance of disability as a human rights issue in the United States, with the 1973 Rehabilitation Act (Section 504) prohibiting federally funded programs from discriminating against people with disabilities (Fleischer and Zames 49-56). Two years later, the American Coalition of Citizens with Disabilities provided community organizations and individuals with a national platform for the first time.

As a cultural and commercial phenomenon of the 1970s and early 80s, the retelling of Merrick’s story is inescapably anachronistic — a modern morality play with a Victorian message. In his review of the film for *New Society*, the historian Raphael Samuel called it an “evangelical fable” with “marked resemblances — not least in its capacity to draw tears — to those ‘moral and improving’ stories which used to be given away as Sunday school prize books” (315). Looked at through a wider lens, however, the fascination with the elephant man reflects changing attitudes towards disability and disfigurement. In 1980, disfigurement was formally recognized as a social impairment by the World Health Organization (30, 106), a decision that paved the way for the inclusion of disfigurement in the

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<sup>2</sup> The term “elephant fever” is used by Michael Cohen, the clinical geneticist who proposed Proteus Syndrome as an alternative diagnosis in 1986 (277).

Americans with Disabilities Act. Although these developments are evidence of an increasing awareness of the social stigma of visible difference, surgery was still seen as the ultimate solution for people whose appearance deviated from the norm. Two world wars had hugely expanded the technical possibilities of plastic surgery and elevated the professional status of plastic surgeons. By the 1970s, the idea of incurable ugliness had been tempered by the expectation (if not always the success or affordability) of surgical intervention. When Lynch's Treves (Anthony Hopkins) tells Merrick, "[w]e can care for you, but we can't cure you," we cannot help but feel "a kind of superiority," writes Martha Bayles in *Harper's*, "because today we could conceivably say, 'Yes. We can cure you. Or at least control your illness through surgery'" (68).

"Elephant man's disease" (at the time identified as the genetic disorder von Recklinghausen neurofibromatosis) piqued the interest of the medical profession as well as the general public. Philip Anglim appealed to Congress for more funding for research (Ablon 1484). Journalists detailed the prevalence and symptoms of this little-known condition and the "bold" surgery that offered some hope to sufferers (Severo C1). Despite this publicity, the critics never wonder what people with appearance-altering conditions like neurofibromatosis might think of Merrick's spectacular ugliness. Without exception, they assume a non-disfigured or "normate" viewer. The *Chicago Tribune* reviewer is not alone in assuming that the film is addressed to the "many people – maybe most people" who are "troubled deeply by persons with deformities," who "even prefer not to be seen with ugly people" (Siskel D5).

Rosemarie Garland-Thomson has used the term *normate* as a way of calling attention to the cultural production of "the normal," a concept in need of constant policing, a line in the shifting sands of human variation that is forever being redrawn. The normate, she writes, is "the figure outlined by the array of deviant others whose marked bodies shore up the normate's boundaries" (*Extraordinary Bodies* 8). For this "unmarked" collective, the elephant man's totemic ugliness is something to marvel at and contemplate, not identify with. This is especially clear in Pomerance's play where Merrick serves as a mirror for the other characters. His body is an object lesson. It teaches us that we are all, in our own way, collectively and individually, deformed. As Bayles says facetiously in her review of the play, "[t]he true deformity, ladies and gentlemen, is society!" (66).

One of a handful of contemporary sources that unmasks the normate *we* is an anonymous letter to the *Chicago Tribune* published in December 1980 ("Voice of the People" E2). The author, who reveals that she has von Recklinghausen neurofibromatosis (as well as a loving family, friends who are comfortable with the way she looks, and a professional career) relates an incident that occurred at the New York theatre where she saw Pomerance's play. Sitting in her seat during the intermission, she overheard the woman behind her reading from the playbill: "There are 100,000 Americans afflicted with VRN." "Well, I never met one," came her companion's reply. The writer gamely turned around, extended her hand, and announced, "I'm one." The woman gasped, the lights went down, and the couple's seats were empty at the end of the performance. It was this experience that prompted the letter to the *Tribune*. Addressing her readers directly, she asks: "Will the portrayal in the play and the movie as well as the comments of the critics color or determine your perception of those with the disease?"

Most printed sources, including reviews of the film and play, start by invoking the *real* elephant man. "The time is the late 1880s and the place is London," begins Vincent Canby's article in *The New York Times* (C8). Many film critics borrow words and phrases from the *Paramount Press Book*, which promises the "true-life story of John Merrick . . . a man so hideously deformed that he was condemned to a life as a freak in a circus sideshow." These historical preambles serve to acquaint readers with the outlines of the narrative, but more than that, they locate the "true" freakishness of the elephant man in a time and place that is almost unimaginably distant from New York, Los Angeles, or Chicago in

1980. Universal truths there may be, but we understand that Merrick's body is a thing of the past. What the modern state "really does with its monsters" is rarely the subject of speculation (Turner 26).

### Modernity's monsters

In his December 1980 *London Review of Books* article on the "flurry of print and picture" surrounding Lynch's film and Pomerance's play, the historian Richard Altick speculated about the timeliness of Merrick's reappearance. The story "has touched a sensitive spot in the contemporary imagination," he ventured:

It has appealed to the witches' brew of anxieties fostered by thalidomide babies and the more recent products of teratogenic drugs, by the victims of Hiroshima and of the mercury wastes in Minamata Bay, by Fellini films and the horror movies on late-night television, by Science fiction with its range of mutants, by controversies over the morality of therapeutic abortion, the emergence of "genetic engineering" and of its capacity to produce fresh monstrosities in laboratories.

Altick's roll call of damaged and dystopian bodies reveals that the nominal boundary between history and myth is as porous today as it was in the past. It is by no means an exhaustive list either: We could add Rachel Carson's exposé of the environmental damage caused by DDT in 1962,<sup>3</sup> and the toxic legacy of America's involvement in the Vietnam War, which resulted in up to 4.8 million civilians being exposed to dioxin between 1962 and 1971 through the use of the defoliant Agent Orange (Biggs). Unlike the immediately visible effects of napalm, which caused severe burns and asphyxiation, the effects of dioxin were delayed. Causing changes at the level of DNA, the compound was initially linked to an increase in cancer in US troops and Vietnamese citizens, then miscarriages and birth defects including missing or deformed limbs, cerebral palsy, spina bifida, and cognitive impairment.

Vietnam veterans took the dioxin tragedy back home with them and spent decades fighting for compensation (Fleischer and Zames 178), but it was another chemical that brought the horror of "monstrous births" into the heart of suburban America. Thalidomide had been widely available in Europe under various trade names, in cough syrups, sleeping pills, and anti-nausea drugs, and had been heavily promoted globally by British and German pharmaceutical companies in the 1950s. Although its use was restricted by the Food and Drug Administration (FDA) in the US, the pharmaceutical company Richardson-Merrell had distributed samples to GPs as an unlicensed, experimental drug and more than twenty-thousand pills had been handed out to patients (Reagan 58). The first sign that something was wrong came in 1961, when German pediatricians noticed a threefold increase in the number of babies born with phocomelia (shortened limbs), normally a very rare congenital malformation. Thalidomide's effect on developing fetuses — as well as an increased risk of miscarriage, stillbirth, and early infant death — was established the same year. By the summer of 1962, the story that thousands of babies had been harmed by a drug prescribed for morning sickness was making headlines around the world.

Although cases were concentrated in Europe, where thalidomide had been available over the counter, the revelation caused shock waves in the United States as well. *Saturday Review's* science editor called it an "epidemic of infant monsters" (Lear 37). "Exclusive First Photos: 5,000 Babies Born with 'Seal Flippers'" was the headline in the August 12, 1962 edition of the *National Enquirer*, a tabloid sold at

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<sup>3</sup> DDT (dichloro-diphenyl-trichloroethane) was the first synthetic insecticide to be used on an industrial scale in the 1940s. Rachel Carson, a marine biologist and conservationist, established that pesticide use in homes, gardens, and farms across America was poisoning food chains. Her book *Silent Spring* was serialized in the *New Yorker* in the summer of 1962 and published later that year.

drugstores and newsstands across the country (Reagan 60). The American cardiologist Helen Taussig, a pioneer of heart surgery for “blue babies,” described the cases in Germany as “the most ghastly thing you have ever seen” (qtd. in Plumb 58). Clinical photographs from Taussig’s June 1962 report in the *Journal of the American Medical Association* were shown in television news broadcasts and circulated in the press. In her study of pregnancy, disability and abortion in modern America, Leslie Reagan highlights the role played by these images in galvanizing the public response to the tragedy (60-61).

The thalidomide scandal provoked questions about the viability and value of human life that were foundational for the development of bioethics and disability studies as academic fields in the 1960s, a decade that also saw intense debate in the United States surrounding the first definition of brain death, and the first successful lung, liver, and heart transplants (“Timeline”). *The Elephant Man* is not *about* thalidomide, but it does address the question of how to love the apparently unlovable; how to live with modernity’s “mistakes” – the drugs that inadvertently cause catastrophic harm, the devastating consequences of chemical weapons, the power of science to damage and maim as well as to heal and improve. People “learn[ed] to love” Merrick, said Lynch before the film’s release. “We think it can happen again” (“‘Elephant Man’ Film not from B’way Hit” 52).

The story of the elephant man reminds us that medicine cannot always cure society’s “incurables,” it can only provide “care.” And caring, in every version of this story, is disproportionately the preserve of women: Treves’s gentle wife Ann (Hannah Gordon), who welcomes Merrick into the family home for afternoon tea; the luminous Mrs. Kendal (Anne Bancroft), who kisses him chastely on the cheek and declares that he is Romeo; Princess Alexandra (Helen Ryan), a fairy godmother who intercedes on Merrick’s behalf and invites him to the royal box at the theatre; and above all the matron, Mrs. Mothershead (Wendy Hiller), who shows through her brisk but attentive actions that care is “the nurse’s province, not the surgeon’s” (Graham and Oehlschlaeger 144). Although reluctant at first to help Treves with his ill-conceived project (she reminds him that Merrick is not a “real patient”), Mrs. Mothershead ends up castigating the surgeon for allowing Merrick to become a visitor attraction. When Treves questions the genuineness of her concern, she snaps:

I bathed him, I fed him, and I cleaned up after him, didn’t I? . . . If loving kindness can be called care and practical concern, then I did show him loving kindness, and I’m not ashamed to say it. (*The Elephant Man* 01:12:46-01:13:06)

Merrick is the eternal child, all “innocence and wonder” (Lynch in Bromell 16). In the film, there is a print of a sleeping boy in his room, and it is this that Merrick looks at before carefully removing the pillows from his bed and lying down on his back. From Montagu onwards, the story of the elephant man orbits around the absent mother. In Lynch’s version, we see her in Merrick’s troubled dreams, in the framed photograph that he cherishes, and in his dying vision of eternal/maternal love. “She has the face of an angel,” Merrick tells Treves’s wife, showing her the miniature portrait. “I must have been a great disappointment to her” (*The Elephant Man* 01:01:18-01:01:45).

Merrick’s unshakable belief in his mother’s goodness and beauty is already present in *Reminiscences*, although Treves assumed that she must have abandoned him as a child (26). The story of the circus elephant is also recorded by Treves, evidence that “maternal impression” continued to be a popular explanation for congenital deformities through the nineteenth century (Treves, “Congenital Deformity”). Nor was it merely a folk belief, suggests Nadja Durbach, who cites serious debate in the *British Medical Journal* on the subject in the 1880s (“Elephant Man” 200). In the screenplay, the incident becomes a founding myth of maternal rape, relocated from the circus to the African jungle:

CLOSE-UP of elephant ears, trunks, faces moving. Dark, heavy feet stomping elephant trumpet, rearing up. Powerful hit and the Mother falls. Darker. Trunk slides Mother's face and breasts and stomach, leaving a moist trail.

MOTHER'S POV of elephant's mouth, eyes, skin. Mother's face twists and freezes in a blurred snap roll. (De Vore et al.)

The "moist trail" did not make it to the final cut, but this remains a scene of sexual violation, the traumatic origin of a monstrous birth. Part human child, part elephant, the hybridity of Merrick's body placed him squarely in the domain of the gothic, "between species: always-already in a state of indifferentiation, or undergoing metamorphoses into a bizarre assortment of human/not-human configurations" (Hurley 10). It also reprises Lynch's previous experiment in disfiguration, *Eraserhead*, released just a few years earlier in 1977 and on its way to becoming a classic on the midnight-movie circuit (Bromell 14, Kaleta 38-40). Featuring a mysterious pregnancy, a cosmic worm-fetus, an armless and legless newborn swaddled in bandages, and a world-ending act of infanticide, *Eraserhead* was, in Lynch's words, "a dream of dark and troubling things" (Leigh).

In his chapter on "Teaching Freaks" in Rosemarie Garland-Thomson's *Freakery: Cultural Spectacles of the Extraordinary Body*, Brian Rosenberg divides modern representations of "the freakish" into two basic mythopoeic types, both with roots in the gothic tradition. Horror cinema provides countless examples of the first, presenting the freak as "an embodiment of our darkest nightmares, something alien not to be disturbed or challenged" (306). Henry's baby in *Eraserhead* is that kind of freak: a darkly comic avatar of parental anxiety. Alternatively, Rosenberg continues, freaks are "sentimentalized into objects of intense pathos, becoming stand-ins for the modern, sensitive-thus-alienated individual." *The Elephant Man* is mentioned in passing as an example of the second kind, which may seem odd given the film's flirtations with horror, but makes sense when we think of it instead as a fairy story or "evangelical fable" aimed at our moral education. Gene Siskel likened the film to Steven Spielberg's *Close Encounters of the Third Kind* (1977), saying that it left him with a profound sense of sadness "that we haven't been able to communicate with the creature." Both films, he concluded, are a "plea for human contact" (D5). Lynch admitted to identifying with Merrick as an outsider and described him as "a beautiful symbol, the perfect thing to bring out the good in people" (Bromell 16). Anglim saw him as a metaphor for "the artist, the irregular, the abnormal outcast from society" (Berkvist 18). He is "Beauty and the Beast" (Birnkranz R4) the "Sweet Innocent" and the "Saintly Sage" (Norden 282).

### **"A tragic syndrome"**

The tendency to see something of ourselves, individually or collectively, in the elephant man confirms Garland-Thomson's claim that "the extraordinary body is fundamental to the narratives by which we make sense of ourselves and our world" (*Freakery* 1). In this sense, freaks are always a mirror of society; always for others rather than for themselves. Yet myths and fables are also constitutive — they create as well as reflect our reality — and their meaning-making effects are unpredictable. One of the unintended twists in this particular story is its impact on people living with neurofibromatosis. In 1988, the American anthropologist Joan Ablon started contacting individuals and families through neurofibromatosis support groups in Northern California. By this time the elephant man was "a household phrase, a metaphor for the grimmest extreme of ugliness" (1482). Merrick's legacy was double-edged, she found, driving popular and scientific interest in this under-reported genetic condition (and generating much-needed funding for research), but also causing "dread and horror" for many of those affected (1488). As one neurologist confided, "it scared the hell out of patients, particularly parents who would go crazy thinking that their child would grow into this monstrosity" (1485).



Neurofibromatosis type 1 (NF1) is a progressive condition caused by an inherited or spontaneous mutation of the tumor suppressor gene on chromosome 17. It is associated with changes in skin pigmentation and a risk of developing benign or malignant tumors (neurofibromas) along the peripheral nerves, potentially affecting the face, hands and feet, the area around the spine, and internal organs. Usually diagnosed in early childhood, it is estimated to affect 1 out of every 3,000 people (Brosius 334), making it more common than better-known genetic disorders like muscular dystrophy and cystic fibrosis. The most distinctive characteristic of NF1 — and its “most damaging psychological feature” according to Ablon — is its unpredictability, with the rate of progression and manifestation of the disease varying enormously, even in members of the same family (1481-82). It is this unpredictability that made the elephant man phenomenon so traumatic because, as Ablon explains, for many people with NF1, where there are no immediate relatives with the disorder, the elephant man was the only role model they had (1485). “I think the Elephant Man is the biggest disservice ever done to people with NF1,” said one genetic counselor she interviewed. “Everyone comes wondering if they will look like that” (1485).

Of the 60 informants interviewed by Ablon, over half of the adults said that the association of their condition with the elephant man had triggered depression, fear, or anxiety. Most of the mothers who took part in the study “expressed horror at the thought of associating their child with the image of the Elephant Man” (1486). Their responses to the film and play show that Merrick’s retrospective diagnosis had by then become a crucial element of the story’s realism for those who believed that they, or their children, shared the same genetic code. “I cried. I identified with him,” said one woman. Another admitted to feeling “hysterical” after she saw the play, “because it was tapping into the awfulness of what my body looks like” (1486). If the normative gaze turns the freak into a spectacle of “absolute Otherness” or casts the extraordinary body as a metaphor for the “secret self,” Ablon’s interviewees show us other possibilities (Fiedler, “Foreword” xiii). For them, Merrick’s ugliness is not a metaphor for cultural anxieties or modern alienation, not an obstacle to be heroically overcome; it is a site of embodied identification.

Although it was first described in 1882, several years before Treves’s visit to the penny gaff on the Mile End Road, von Recklinghausen’s disease was not proposed as a diagnosis until 1909, based on an analysis of Merrick’s skeleton in the London Hospital (Weber 51). When the gene for NF1 was identified in 1990 and Merrick’s bones were tested, a negative result cast doubt on the original theory and opened the door to further speculation. As recently as 2013, the BBC commissioned a Radio 4 documentary aimed at “Unlocking the Secrets of Elephant Man” (Bomford). The most widely accepted alternative diagnosis is Proteus syndrome, an extremely rare condition named after the shape-shifting sea-god of Greek mythology (Tibbles and Cohen). But the association with neurofibromatosis persisted, in spite of the rediagnosis, in part because “the elephant man” had become synonymous with “ugliness [at] its possible worst” (Ablon 1488). As one informant put it: “Even though we know now that ‘the Elephant Man’ didn’t have NF, people with NF are still treated like that when they go outside. Even though we have supposedly modernized, . . . any kind of deformity is still repulsive and cannot be accepted” (qtd. in Ablon 1488). The conviction that disfigurement is profoundly stigmatizing, whatever its cause, appears in journalistic reports of “Elephant man’s disease” as well as in the medical and anthropological literature. Merrick “had the kind of disease nightmares are made of – neurofibromatosis,” the *Boston Globe* informs its readers (Earley 35). “People still get it – did you know that?” Mel Brooks asks during an interview. “It’s tough to look at. That’s one reason we’re shooting the film in black and white – colour would be too horrible” (Mann W31). A *New York Times* article on one woman’s experimental surgery for “‘Elephant Man’ disease” describes NF as a “curse at birth in a single, dominant gene” (Severo C8). “Her face just won’t allow people to react normally to her,” explains Dr. Linton Whitaker, the plastic surgeon leading the team of four principal surgeons at the University of Pennsylvania hospital. It is not a matter of beauty, says his patient, Lisa H., adding, “I

don't want to look like Farrah Fawcett-Majors." It is about the right to live "unobtrusively, unspectacularly, normally" (Severo C8).

The elephant man comes to represent the "curse" of any congenital disfigurement. We see this happening as early as 1973, when the Canadian plastic surgeons Theodore Wilkie and J. Milton Rabson propose using the term "elephant man syndrome" for "those who are made so ugly by certain congenital conditions that they are unable to function happily" (327).<sup>4</sup> What is novel in their account is the emphasis on psychosocial factors. Although the initial manifestation of the "syndrome" is physical, its most devastating characteristics are "social rejection" and the "psychic deformation" that results from it (328). This "triad" of physical, social, and psychological elements reflects an understanding of disfigurement that has nothing to do with Frederick Treves, who saw Merrick through the lenses (overlapping, rather than distinct) of gothic literature, Enlightenment medicine, and Victorian Christianity. It is only tenuously inspired by Montagu's 1971 book, which presents Merrick as miraculously unscarred by his misfortunes. "What made his case so interesting," wrote Montagu in 1982, in the newsletter of the National Neurofibromatosis Foundation, "was that in spite of his physical and mental suffering, he turned out to be a most gentle, generous, and indeed, charming character" (qtd. in Ablon 1483).

Wilkie and Rabson's paper reflects a paradigm shift in thinking about disfigurement that is indebted to the pioneering work of another medical anthropologist, Frances Cooke Macgregor (1906-2002), who began to investigate the social and psychological implications of visible difference in the 1950s and whose research informed the World Health Organization's recognition of disfigurement as a social impairment in 1980. In a 1981 article in *Aesthetic Plastic Surgery*, she wrote about the "psychological wounds" that children with disfigurements often carried with them through adult life and "the obsessive concern with looking young and beautiful" that was so much a part of contemporary American culture (21, 24). In this context, even minor imperfections can be socially significant; indeed, "there is no proportional relationship between the degree of the severity of the defect and the psychic distress it can generate" (Macgregor 20). Her debt to Erving Goffman's account of stigma is evident in expressions like "visible stigmata" (in reference to the distinctive facial markers of Down's syndrome) and in her insistence that the cultural meanings attributed to visible difference should inform clinical decisions.

Macgregor's career coincided with the birth of the disability rights movement and academic disability studies, and her research, like Ablon's, has played a part in elaborating a social model of disability and visible difference (Shuttleworth and Kasnitz 151). But the only solution she considers is a medical one. Just as Wilkie and Rabson promoted aesthetic surgery as a potentially "life-saving" treatment for "repulsive disfigurement" (336), Macgregor advocated corrective surgery for "aesthetic defects" ("Place of the Patient" 19). Aesthetic plastic surgery was, in her view, "an important therapeutic speciality whose essential function is to improve quality of life" (26). There is no suggestion in these texts — or in any of the reviews of *The Elephant Man* — that social expectations and standards of attractiveness might be challenged or expanded. The solution to ugliness is surgical rehabilitation, not legal protection or attitudinal change. Merrick's reincarnation on stage and screen coincided with a newly socially-inflected understanding of disfigurement, but responses to the film and play attest to the resilience of a medical model in which medical diagnosis is the gold standard for understanding bodily difference (Durbach, "Elephant Man" 200) and where treatment entails the "normalization" of individual bodies (Macgregor, "Place of the Patient" 26).

For the neurofibromatosis community, medical progress was what stood between them and the elephant man. The letter published in the *Chicago Tribune* ends with the observation that "none of us

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<sup>4</sup> Wilkie and Rabson's paper was presented at the Annual Meeting of the American Society for Aesthetic Plastic Surgery in March 1973.

with von Recklinghausen neurofibromatosis — especially on the face — could have much freedom . . . were it not for plastic surgery. Men and women dedicated to this speciality provide us with the appearance standard most expect and require in our society – even to dine in a restaurant” (“Voice of the People” E2). Ablon’s informants, too, weigh the pros and cons of the interest generated by *The Elephant Man* and in all but a few cases decide that it was worth it, because public attention means more research and better treatments. “The end result is money,” says one interviewee pragmatically. “I think the end justifies the means,” offers another (1487). But the medical model has never been ideologically neutral, and every version of Merrick’s story contains a moral. “As a hospital patient,” writes Raphael Samuel, “Merrick is the very incarnation of that favourite subject of the 19<sup>th</sup> century evangelical imagination — the moral and deserving poor.” Quiet, grateful, never angry or demanding, he is “a monument to patient suffering” (315). “One longs for an explosion of rage,” is Vincent Canby’s comment on Hurt’s performance, noting how perfectly he exemplifies the New Testament virtue of meekness (C8).

Even in Ablon’s conclusions we find traces of Treves’s dualism when she contrasts Merrick’s “shocking physical appearance” to his “strength of character” and the “courage and dignity that have made it difficult for many to simply walk away from that haunting image” (1488). For disability rights activists who were trying to reclaim disabled and visibly different bodies as a site of agency, identity and beauty, the elephant man was not a helpful role model (Darke). As told by Treves, Montagu and Lynch, his story teaches us that dignity and kindness matter above all — more than human rights or changing society — and that the material body is less important than the soul.

## Conclusion

There are other ways of telling Merrick’s story. Nadja Durbach contrasts Treves’s establishment view of Merrick (as a cruelly exploited invalid) with the account of Tom Norman, his London manager and one of the most successful showmen of his generation. Norman met Merrick in 1884 when both men were in their twenties. His memoirs, which resurfaced when Howell and Ford were researching their book, provide a counter-narrative of the Victorian freak show and another way of thinking about the exhibition and commodification of physical difference. “By advertising freaks as healthy rather than diseased,” writes Durbach, “and as remarkable rather than disgusting, these types of exhibitors also allowed for human diversity and celebrated bodily variation.” With a nod to the literary and cultural critic Leslie Fiedler, she suggests that freak shows played a part in resisting “the tyranny of the normal” (*Spectacle of Deformity* 29).

Fiedler’s own conception of the “true freak” — an epithet he extends to phocomelics (from the Greek words for *seal* and *limb*) and to the elephant man — is unapologetically essentialist. His 1978 book *Freaks: Myths and Images of the Secret Self* is a homage to wild, extravagant difference, and to the folk traditions that sustained and celebrated it before the advent of cinema. When he writes about the transition from the carnival to the movie theatre, “from the platform and the pit to the screen,” it is with a sense of regret — “flesh becoming shadow” (16). His book, which has a chapter on the elephant man, springs from an American cultural fascination with the freak and the freak show that took a multitude of forms including Diane Arbus’s photographs of Eddie Carmel, the “Jewish giant,” and other carnival performers. “There’s a quality of legend about freaks,” Arbus later said. “Like a person in a fairy tale who stops you and demands that you answer a riddle” (Arbus 3).

It is with the same note of reverence that Fiedler gives Merrick the title of “the Ugliest Male who ever lived” (*Freaks* 170). Freakishness for Arbus and Fiedler, and I think for David Lynch, is like genius or exceptional beauty: a matter of birth, not accident or effort. As Rosenberg says of Fiedler’s approach, it is “very nearly the freak as art-object, described in terms usually reserved for painting and poems” (306). This has not been a popular view since the publication of Robert Bogdan’s *Freak Show*:

*Presenting Human Oddities for Amusement and Profit* in 1988, a book that reoriented the field of freak studies towards sociology and social history. By showing how freaks are made, not born, Bogdan challenged Fiedler's essentialism with constructionism (Cassuto 247-48). "'Freak' is not a quality that belongs to the person on display," he claims; "it is something that we created: a perspective, a set of practices — a social construction" (Bogdan xi).

These have been necessary disciplinary adjustments, but Lynch's film insists that extraordinary bodies *can* be aesthetic objects — like paintings or poems — and as such demand, and reward, interpretive effort. It is the generative quality of the aesthetic object that makes Merrick's body (and not just his story) so enduringly fascinating. Raphael Samuel recalled seeing *The Elephant Man* for the first time and coming out of the cinema with a feeling of "intense resentment at the way it travestied history, and at the same time an uneasy sense of its power" (315). It has not been my intention to point out the ways in which Lynch and Pomerance got things wrong about the past (Samuel's coruscating review does an excellent job of that). Instead, I have made a case for understanding Merrick's reappearance as a phenomenon of the 1970s and 80s. Ostensibly a tale about Victorian London, it became a modern parable of tragic ugliness and inner beauty at a time when disfigurement was being redefined as a disability, and disability was finally being recognized as a civil rights issue. Like all historical shifts, these events have an infinitely more complicated relationship with cultural production than the term "context" usually implies. Hurt's portrayal of Merrick draws on a tradition of the mythopoeic grotesque that has passed through countless iterations from Pliny the Elder's "monstrous races" in the first century CE to Todd Phillips and Joaquin Phoenix's *Joker* (Collins). But the film also tapped into contemporary anxieties about genetic mutation and monstrous birth, and informed the way neurofibromatosis and other potentially disfiguring conditions were seen: as a "curse" that could finally be broken by modern medicine.

### Works Cited

- Ablon, Joan. "'The Elephant Man' as 'Self' and 'Other': The Psycho-Social Costs of a Misdiagnosis." *Social Science & Medicine*, vol. 40, no. 11, 1995, pp. 1481–89.
- Altick, Richard. "Pity the Monsters." *London Review of Books*, vol. 2, no. 24, 18 Dec. 1980, [www.lrb.co.uk/the-paper/v02/n24/richard-altick/pity-the-monsters](http://www.lrb.co.uk/the-paper/v02/n24/richard-altick/pity-the-monsters). Accessed 10 Aug. 2020.
- Arbus, Diane. *Diane Arbus: An Aperture Monograph*. Aperture Foundation, 1972.
- Bayles, Martha. "Deformation of Character." *Harper's*, 1 May 1981, pp. 66-68.
- Behind the Shadow of Merrick*. Directed by David Hevey. University of Leicester / Research Centre for Museums and Galleries, 2008.
- Berkvist, Robert. "Philip Anglim Turns a Freak into Reality." *The New York Times*, 21 Apr. 1979, p. 18.
- Biggs, David. "Vietnam: The Chemical War." *The New York Times*, 24 Nov. 2017, [www.nytimes.com/2017/11/24/opinion/vietnam-the-chemical-war.html](http://www.nytimes.com/2017/11/24/opinion/vietnam-the-chemical-war.html). Accessed 12 Jun. 2020.
- Birnkrant, Sam. "The Disfigured Appeal of the Elephant Man." *Los Angeles Times*, 13 Jul. 1980, p. R4.
- Blau, Eleanor. "Will Viewers 'See' this 'Elephant Man'?" *New York Times*, Dec 27, 1981, p. D25.
- Bogdan, Robert. *Freak Show: Presenting Human Oddities for Amusement and Profit*. U of Chicago P, 1988.
- Bomford, Andrew. "Unlocking the Secrets of the Elephant Man." BBC News, 29 Aug. 2013, [www.bbc.co.uk/news/magazine-23863974](http://www.bbc.co.uk/news/magazine-23863974). Accessed 17 Aug. 2020.
- Bromell, Henry and David Lynch. "Visionary from Fringeland." *Rolling Stone* 330, 13 Nov. 1980, pp. 13-19.
- Brosius, Stephanie. "A History of von Recklinghausen's NF1." *Journal of the History of the Neurosciences*, vol. 19, no. 4, 2010, pp. 333–48.
- Canby, Vincent. "'Elephant Man,' Study in Genteelness." *The New York Times*, 3 Oct. 1980, p. C8.

- Cassuto, Leonard. "Freak." *Keywords for Disability Studies*, edited by Rachel Adams et al., New York UP, pp. 246-53.
- Chaillet, Ned. "The Beginning of a Cult Industry." *Times*, 16 Jul. 1980, p. 11.
- Champlin, Charles. "Portrait of the Monster as a Human Being." *Los Angeles Times*, 28 Sept. 1980, p. T34.
- Cohen, Michael, Jr. "Understanding Proteus Syndrome, Unmasking the Elephant Man, and Stemming Elephant Fever." *Neurofibromatosis*, vol. 1, no. 5-6, 1988, pp. 260-80.
- Collins, Sean T. "The Complete History of the Joker." *Rolling Stone*, 16 Dec. 2019, [www.rollingstone.com/movies/movie-features/complete-history-of-the-joker-889033/](http://www.rollingstone.com/movies/movie-features/complete-history-of-the-joker-889033/). Accessed 19 Aug. 2020.
- The Curse of the Elephant Man*. Directed by Malcolm Hall. National Geographic New Zealand, 2003.
- Darke, Paul Anthony. "The Elephant Man: An Analysis from a Disabled Perspective." *Disability & Society*, vol. 9, no. 3, 1994, pp. 327-42.
- De Vore, Christopher, et al. *The Elephant Man*. Internet Movie Script Database (IMSDb), [www.imsdb.com/scripts/Elephant-Man,-The.html](http://www.imsdb.com/scripts/Elephant-Man,-The.html). Accessed 10 Aug. 2020.
- Dimmer, Frederick. *Very Special People: The Struggles, Loves, and Triumphs of Human Oddities*. Amjon, 1973.
- Durbach, Nadja. "Monstrosity, Masculinity and Medicine: Re-Examining 'the Elephant Man.'" *Cultural and Social History*, vol. 4, no. 2, 2007, pp. 193-213.
- Durbach, Nadja. *Spectacle of Deformity: Freak Shows and Modern British Culture*. U of California P, 2009.
- Earley, Sandra. "'Elephant Man' Enhanced by Television." *Boston Globe*, 4 Jan. 1982, p. 35.
- The Elephant Man*. Directed by David Lynch. Brookfilms, 1980.
- "The Elephant Man (1980)." *AFI Catalog*, <https://catalog.afi.com/Catalog/moviedetails/56402>. Accessed 20 Apr. 2020.
- "The 'Elephant Man.'" *British Medical Journal*, vol. 2, no. 1354, 11 Dec. 1886, pp. 1188-9.
- "'Elephant Man' Film not from B'way Hit; Same Title." *Variety*, vol. 295, no. 2, 16 May 1979, p. 52.
- Fiedler, Leslie. *Freaks: Myths and Images of the Secret Self*. Penguin, 1981.
- Fleischer, Doris Zames and Frieda Zames. *The Disability Rights Movement: From Charity to Confrontation*. Temple UP, 2011.
- Garland-Thomson, Rosemarie. *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*. Columbia UP, 2017 [1997].
- Garland-Thomson, Rosemarie, editor. *Freakery: Cultural Spectacles of the Extraordinary Body*. New York UP, 1996.
- Graham, Peter W. and Fritz Oehlschlaeger. *Articulating the Elephant Man: Joseph Merrick and His Interpreters*. Johns Hopkins UP, 1992.
- Howell, Michael, and Peter Ford. *The True History of the Elephant Man*. Allison and Busby, 1980.
- Hurley, Kelly. *The Gothic Body: Sexuality, Materialism, and Degeneration at the Fin de Siécle*. Cambridge UP, 1996.
- Hurt, John. StudiocanalUK interview. *YouTube*, [www.youtube.com/watch?v=E-50BaRLacU](http://www.youtube.com/watch?v=E-50BaRLacU). Accessed 14 Apr. 2020.
- Kaleta, Kenneth C. *David Lynch*. Macmillan, 1993.
- Kuhn, Joy. *The Elephant Man: The Book of the Film*. Virgin books, 1980.
- Lear, John. "The Unfinished Story of Thalidomide." *Saturday Review*, 45, 1 Sep. 1962, p. 37.
- Leigh, Danny. "Eraserhead: The True Story behind David Lynch's Surreal Shocker." *The Guardian*, 22 Mar. 2017, [www.theguardian.com/film/2017/mar/22/david-lynch-eraserhead](http://www.theguardian.com/film/2017/mar/22/david-lynch-eraserhead). Accessed 17 May 2020.
- Loder, Kurt. "Scary Monster on Broadway." *Rolling Stone*, 13 Nov. 1980, pp. 8-11.
- Macgregor, Frances Cooke. "The Place of the Patient in Society." *Aesthetic Plastic Surgery*, vol. 5, 1981, pp. 19-26.

- Mann, Roderick. "Brooks Gets Serious About 'Elephant Man.'" *Los Angeles Times*, 28 Oct. 1979, p. W31.
- Meet the Elephant Man*. Directed by Mark Radice. Windfall Films, 2011.
- Montagu, Ashley. *The Elephant Man: A Study in Human Dignity*. Allison & Busby, 1972.
- Montagu, Ashley. *The Elephant Man: A Study in Human Dignity*. 2<sup>nd</sup> ed., E. P. Dutton, 1979.
- Norden, Martin F. *The Cinema of Isolation: A History of Physical Disability in the Movies*. Rutgers UP, 1994.
- Paramount Press Book: The Elephant Man*. Paramount Pictures Corporation, 1980.
- Plumb, Robert K. "Deformed Babies Traced to a Drug." *New York Times*, 12 Apr. 1962, pp. 37, 58.
- Pomerance, Bernard. *The Elephant Man*. Faber and Faber, 1979.
- Reagan, Leslie J. *Dangerous Pregnancies: Mothers, Disabilities, and Abortion in Modern America*. U of California P, 2012.
- "Return of the Elephant Man," *Illustrated London News*, 25 Oct. 1980, p. 25.
- Richards, Sean, editor. *The Elephant Man and Other Freaks*. Futura, 1980.
- Rosenberg, Brian. "Teaching Freaks." *Freakery: Cultural Spectacles of the Extraordinary Body*, edited by Rosemarie Garland-Thomson, New York UP, 1996, pp. 302-11.
- Samuel, Raphael. "The Elephant Man as a Fable of Class." *New Society*, 19 Nov. 1981, pp. 315-17.
- Severo, Richard. "Woman With 'Elephant Man' Disease Chooses Bold Surgery." *The New York Times*, 8 Dec. 1981, pp. C1, C6.
- Sherman, Kenneth. *Words for Elephant Man*. Mosaic Press, 1983.
- Siskel, Gene. "Hurt Shines in Powerful 'Elephant Man.'" *Chicago Tribune*, 24 Oct 1980, p. A3.
- Siskel, Gene. "Studio Diminishes 'Elephant Man's' Humane Message." *Chicago Tribune*, 26 Oct. 1980, p. D5.
- Sparks, Christine. *The Elephant Man*. Ballantine Books, 1980.
- Shuttleworth, Russell P. and Devva Kasnitz. "Stigma, Community, Ethnography: Joan Ablon's Contribution to the Anthropology of Impairment-disability." *Medical Anthropology Quarterly*, vol. 18, no. 2, 2004, pp. 139-61.
- Taussig, Helen B. "A Study of the German Outbreak of Phocomelia: The Thalidomide Syndrome." *JAMA*, vol. 180, no. 13, 30 Jun. 1962, pp. 1106-1114.
- Tibbles, J. A., and Michael M. Cohen. "The Proteus Syndrome: The Elephant Man Diagnosed." *British Medical Journal*, vol. 293, 13 Sept. 1986, pp. 683-85.
- "Timeline of Historical Events and Significant Milestones." *Organdonor.gov*. Health Resources and Services Administration (HRSA), [www.organdonor.gov/about/facts-terms/history.html](http://www.organdonor.gov/about/facts-terms/history.html). Accessed 20 Apr. 2020.
- Treves, Frederick. *The Elephant Man and Other Reminiscences*. Cassell & Co, 1923.
- Treves, Frederick. "A Case of Congenital Deformity." *Transactions of the Pathological Society of London*, vol. 36, Mar. 1885, pp. 494-98.
- The True Story of The Elephant Man*. Directed by John Hayes-Fisher and Emma Walker. BBC, 1997.
- Turner, E. S. "Victorian Freak." *New Society*, 3 Apr. 1980, p. 26.
- "Voice of the People." *Chicago Tribune*, 2 Dec. 1980, p. E2.
- Weber, Frederick Parkes. "Cutaneous Pigmentation as an Incomplete Form of Recklinghausen's Disease." *British Journal of Dermatology*, vol. 21, Feb. 1909, pp. 49-51.
- Wilkie, Theodore F., and J. Milton Rabson. "The Elephant Man: A Tragic Syndrome." *Aesthetic Plastic Surgery*, vol. 3, no. 1, 1979, pp. 327-37.
- World Health Organization. *International Classification of Impairments, Disabilities, and Handicaps: A Manual of Classification Relating to the Consequences of Disease*. WHO, 1980.