

# Disability History Association News

Fall, 2019

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## Editorial

When Penny Richards stood down from the board of the Disability History Association, in which she had played so many roles in advancing our discipline through a long period of time, our small committee discussed how Penny's activities on behalf of DHA should be redistributed.

This coincided with a period during which DHA was trying to expand its online presence in a variety of forms. Penny had compiled a DHA newsletter for many years. Indeed, it was a key outreach resource to the disability history community. However, by the second decade of the new millennium, were newsletters, even newsletters distributed via email, websites, etc., no longer of appeal to readers when there was also output on Facebook, Twitter, etc? At that point in 2017, DHA thought the newsletter had therefore run its course and, with Penny taking a well-earned retirement, the newsletter was permitted to retire with her.

Was that a wrong decision? At a recent DHA board meeting, despite the Association's expansion into various other forms of outreach, it was felt that we SHOULD also have a newsletter. So, with this issue, following a two-year gap, the DHA Newsletter is back!

In relaunching the newsletter, we are of course, starting with an empty portfolio. This issue tells you about some of the things that are happening in DHA. For example, read about the wonderful podcasts that Caroline Lieffers has been conducting and continues to record. Perhaps YOU would like to feature in one of these – if so, email Caroline at [c.lieffers@gmail.com](mailto:c.lieffers@gmail.com). Read also about the various awards offered by DHA, the outcomes of some of the most recent awards, and opportunities to participate in future awards.

But DHA News should not only be an ‘insider’ perspective. We actively encourage readers to submit articles, stories, etc., on their activities. For the purposes of a newsletter such as this, these need not be overtly academic in style (the Newsletter is not a journal) – include references if you wish, but there is flexibility on this; and something not offered by many academic publications, we also welcome images (but please accompany them with copies of the appropriate permissions if these are from third-party sources).

To, hopefully, set the idea of reader contributions in motion, we turn the clock back a decade by reprinting an article by Alex Wexler. This first appeared in the DHA newsletter in 2009.

Lastly, a word about style. I thought about the format for this edition of the newsletter. Should we come up with a catchy DHA News banner, and introduce a logo and lots of trendy typefaces? However, I then reflected on a blind history project with which I was involved a while ago. The output from this was produced in various formats specifically to make it accessible to an audience which included blind and vision-impaired readers. In this, we were guided by the Royal National Institute of Blind People (RNIB). I learned that accessibility was enhanced by avoiding colour type and by adopting left justification of text. We used a font called Tondo, which was considered as offering optimum accessibility, but this is not a font that is in wide circulation, so I have used Arial – a popular font and one that is quite close to Tondo.

I welcome views on this effort to widen accessibility. Therefore, please, ‘Letters to the Editor’ – on this topic and on anything else that you would like to write about.

Iain Hutchison  
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## DHA Graduate Student Travel Scholarship – report from Greg Carrier

As part of our commitment to promoting the work of disability historians at all career stages, the Disability History Association (DHA) invites graduate students to apply for our conference travel award. The award is meant to support travel to professional academic conferences and is not restricted by geographic location. The fellowship committee will award up to two graduate student applicants \$250 (US) each to support attendance at conferences each year. The Association will cover expenses in currencies other than US dollars as required. Check the DHA website for announcement of the latest award round.

Latest recipient of the award was **Gregory Carrier** (University of Alberta) who presented a paper entitled “Augustine and Aquinas on Modern Disability Theory” and

participated in the roundtable “Medieval Disability and Pedagogy” at the 54th International Congress on Medieval Studies held in Kalamazoo, Michigan, May 9-12, 2019. Gregory’s report follows.

## Augustine, Aquinas, and Lawyers: Medieval Disability Scholarship

This past May, I attended the International Congress on Medieval Studies – affectionately called “the Zoo” by medievalists – at Western Michigan University in Kalamazoo, Michigan. The conference brings together over 3,000 medievalists from around the world to present on and discuss all things medieval, whether it be examining the great philosophical and literary works such as Boethius’ *Consolation of Philosophy* or the influence that *Game of Thrones* has had on popular conceptions of the Middle Ages.

While medieval disability studies has gained both in visibility and popularity since Irina Metzler’s *Physical Impairment During the High Middle Ages, c. 1100-1400* (Routledge, 2006) examining medieval conceptions of disability, one area has not been much examined – medieval theology. The popular idea that disability was seen as a punishment for sin in medieval Europe has influenced disability theory today, most notably through Nancy Eiesland’s *The Disabled God*. Eiesland’s thesis has given rise to the understanding in modern disability studies that theology needs to be “liberated” from a negative perception of disability and transformed into a positive explication of disability.

Through my work examining medieval theological understandings of disability, particularly those of Saints Augustine and Thomas Aquinas, I have come to realise that the idea that medieval thinkers invariably saw disability as a punishment for sin is wrong. Rather, medieval theologians saw disability as a corporate identity shared by all of humanity as a result of our separation from God through Adam and Eve’s disobedience in the Garden of Eden. They would have found modern disability theory’s emphasis upon physical and sensory impairments to be strange precisely because they emphasise the individual and mark him or her out to be different. Medieval thinkers would have focused more upon questions of morality and how our separation from God has “disabled” our ability to make rational and moral decisions, irrespective of our physical and sensory abilities. Put simply, medieval thinkers may very well have considered Adam and Eve’s disobedience to be not only the most disabling event in human history, but also to be the *only* disabling event in all of history. Augustine and Aquinas would thus have seen disability—humanity’s impaired ability to make rational and moral decisions—as a *consequence* of Adam and Eve’s disobedience, and *not* as a punishment for an individual’s personal sins.

The above constituted the basis of my paper titled “Augustine and Aquinas on Modern Disability Theory”, which was very well-received. A number of academics were very intrigued by my conclusions, and frequently commented on how glad they were to see that the topic of disability theology was receiving some attention. The conviviality of the session led to several good comments and questions, all of which I hope to take into account as I develop the paper for eventual publication. I was also very fortunate to meet several Augustinian and Thomistic scholars, who have in turn graciously introduced me to other thinkers in both medieval theology and disability theology; these introductions are enabling me to begin bringing my work into

conversation with modern disability theology and theory, and to show how medieval theological conceptions of disability can positively influence modern disability theology.

In addition to disability theology, I also participated in a roundtable where each participant provided a “mini-talk” on a concrete example of disability in medieval Europe and how it could be incorporated into a disability history course. I discussed three legal cases from thirteenth-century England involving the deaf and hard-of-hearing. I demonstrated how a careful reading of the case summaries—written in Latin—revealed that the courts precisely defined what it meant to be pre-lingually deaf, hard-of-hearing, and post-lingually deafened, and what legal rights and obligations each category of hearing loss presumed. Surprisingly, the courts also consistently upheld the rights of deaf and hard-of-hearing litigants to the point of impinging upon the legal rights of their hearing adversaries in the courtroom. This interpretation stands in stark contrast to the assumption in the scholarship that medieval courts sought to strip the deaf and hard-of-hearing (and, indeed, any other disabled person) of their legal rights whenever possible. I suggested that examining cases such as the ones I mentioned would be helpful in encouraging students to consider questions around legal rights, ableism, and the dignity of the disabled person, issues that are pertinent today.

I would like to once again thank the Disability History Association for its kind support in enabling me to attend “the Zoo”—it was truly a remarkable experience.

Gregory Carrier

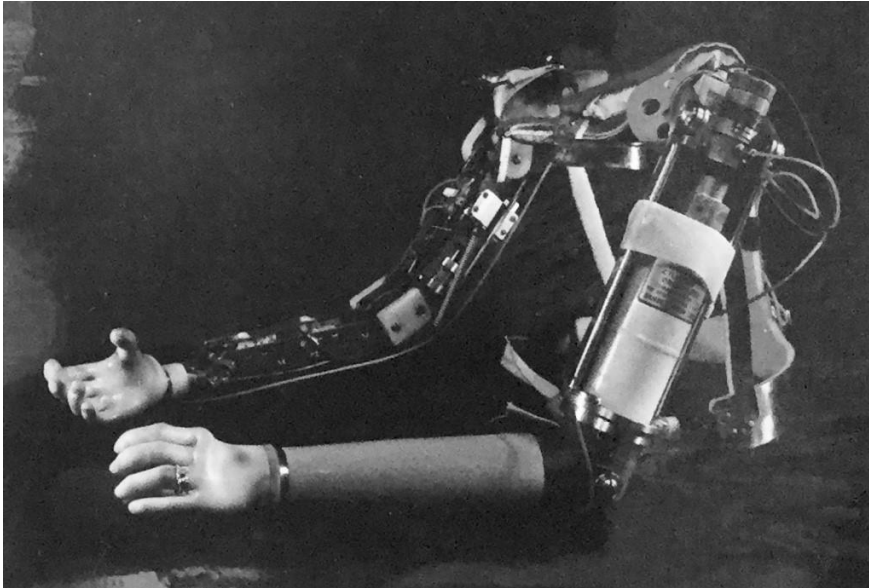
## Bioengineering and Disability

This article is reproduced from the newsletter of the Scottish Records Association, ‘Retour’, 32, Autumn. It is reproduced with the permission of Lothian Health Services Archive (LHSA), Edinburgh, Scotland, with permission.

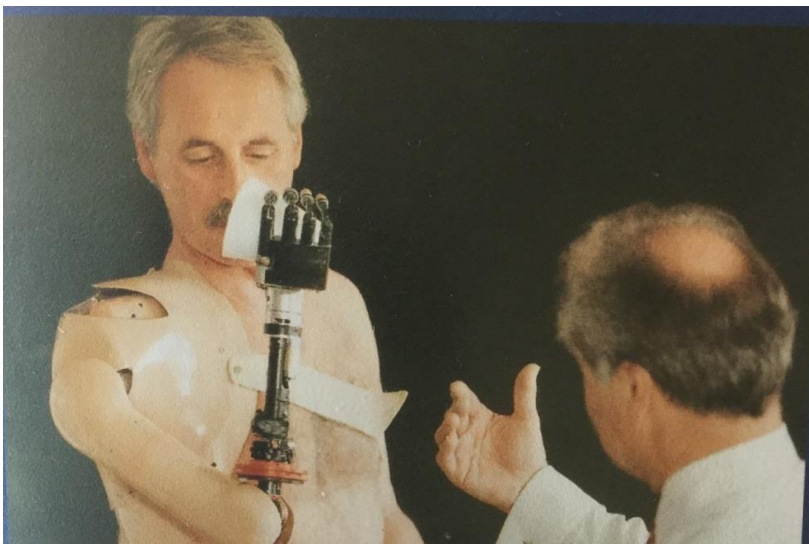
Over the summer of 2019, 3rd year History undergraduate Carmen Hesketh worked at Lothian Health Services Archive by means of the ‘Employ.ed on Campus’ programme, a paid summer internship scheme for University of Edinburgh students. Carmen’s ten-week internship was based on an archive donated to LHSA by bioengineer, David Gow, covering not only his own pioneering work, but also the wider development of bioengineering in Edinburgh. Here are some reflections from Carmen herself: ‘I’m particularly interested in disability history, so I was so excited when I had the chance to be involved in a project about artificial limbs and disability living aids! I have created an online learning resource about bioengineering in Edinburgh from the 1960s to the present day. The Bioengineering Centre at Princess Margaret Rose Orthopaedic Hospital was first opened to create gas-powered prostheses to support those affected by thalidomide. Since News 9 the 1980s, work in Edinburgh has generated pioneering inventions such as David Gow’s Edinburgh Modular Arm System (EMAS), the first electrically powered arm with a powered shoulder, elbow, wrist and fingers, and Gow’s i-limb hand, the first electrically powered hand with articulating digits. I made my resource using Prezi to make it

interactive and engaging. I hope it encourages the public to engage with LHSA's collections and academics to use them in their research!

You can view Carmen's resource and learn more about the history of artificial limb development in Edinburgh from the LHSA webpages, here:



<http://www.lhsa.lib.ed.ac.uk/exhibits/bioengineering.htm> A photograph of a gas powered prosthesis, c.1960s/70s, clearly showing a gas canister placed inside the arm (Acc10/001)



A photograph of Campbell Aird, a hotel manager who lost his arm to muscular cancer, wearing the EMAS, 1998. Campbell Aird enjoyed the publicity of the EMAS arm, and was extremely grateful to David Gow, the inventor of the device, for improving his life (Acc10/001)

Footnote: Dr Louise Williams, LHSA Archivist, writes: This collection is currently uncatalogued so does not, at present, have an online listing. Therefore anyone interested in seeing items in the collection would, as a first step, need to contact LHSA. Carmen's assignment is however intended to generate further research interest in the Gow collection. Louise can be contacted at: [louise.williams@ed.ac.uk](mailto:louise.williams@ed.ac.uk)

## 2018 DHA journal article / book chapter award

DHA takes pleasure in announcing that the **Winner** of the 2018 Journal article / book chapter award is Dr Maria Cristina Galmarini-Kabala for her article:

'Psychiatry, Violence, and the Soviet Project of Transformation: A Micro-History of the Perm Psycho-Neurological School-Sanatorium'. This appeared in *Slavic Review*, 77:2 (Summer 2018), 307-332.

Maria is affiliated with The College of William & Mary, where she holds an Assistant Professor position in the History Department and in the Global Studies Program.



Her article analyzes the interactions of medical experts, minor patients, and parents in a child psychiatric institution that operated in the Soviet city of Perm' between 1926 and 1929. Through a micro-history of this institution, she raises questions about the nature of violence within the realm of psychiatric care, demonstrating the multidimensional flow of power within a particular institutional setting and adding complexity to our understanding of the asylum writ large. At the same time, she engages the question of violence in Soviet society at the end of the New Economic Policy, suggesting that the historical actors involved in the Perm' institution used violence as a means to explain the crisis of their time.

DHA also makes an **Honorable Mention** in respect of the second-placed entry for the award. For 2018, this is Dr Natalie Spagnuolo for her chapter contribution:

'Mobilising historical knowledge: Locating the disability archive', in K Ellis, R Garland-Thompson, M Kent & R Robertson (eds), *Interdisciplinary Approaches to Disability: Looking Towards the Future* (New York: Routledge, 2018), 153-163.

Natalie is a Contract Instructor at Pauline Jewett Institute of Women's and Gender Studies, Carleton University and Co-Director of Memory Witness and Hope/Mémoire témoignages et espoir.



Natalie uses Pieter Verstraete's *In the shadow of disability: Reconnecting history, identity and politics* (Toronto: Barbara Budrich Publishers, 2012) for 'close engagement with the implications he draws through social constructivist claims' that, she argues, 'may spark more nuanced discussion and debate about historical knowledge formation and its relationship to current political struggles. What lies ahead marks a preliminary attempt to embark on such reflections and draws upon postcolonial theories of identity and postcolonial disability studies to consider both the intended and unintended effects of varying tendencies within disability history. Far from a comprehensive survey, the goal of this brief chapter is to begin to probe the tensions and implications of some of the conceptual and epistemological choices that are available to disability historians.' She explains that the purpose of her chapter 'is not to weigh the merits of specific frameworks or narratives ... [but to] explore[] possible complications and raise initial questions about how historical subjects are made, framed and/or located, depending on the view, and it does so by loosely delineating and visiting a sample of arguments forwarded by historians and others concerned with the politics of history writing, asking how different actions and choices might affect disability politics today.'



# Public Disability History Award

Did you complete a public disability history project in the last two years? Was it a community-anchored or community-led project designed with physical and programmatic accessibility in mind?

Apply now to win a new cash award sponsored by the Disability History Association.

Visit our web site (<http://dishist.org>) to learn more about project criteria. Applicants must currently be members of the Disability History Association. You can join or renew your membership on the website.

Submit a cover letter, project description, and other supporting materials such as media coverage to Nicole Belolan, Award Chair and Disability History Association Secretary, **by December 20, 2019**, at [nbelolan@gmail.com](mailto:nbelolan@gmail.com). Questions about the application process are welcome and encouraged. Award will be announced in February 2020.

To learn more about how to make your public disability history work accessible, check out our resource library.

Please help spread the word. You can find this Word doc and other promotional materials at: [http://dishist.org/?page\\_id=1230](http://dishist.org/?page_id=1230).



First biennial

## PUBLIC DISABILITY HISTORY AWARD

Submit by December 20, 2019  
Get more info at [dishist.org](http://dishist.org)

Send questions to [nbelolan@gmail.com](mailto:nbelolan@gmail.com)



## Caroline Lieffers writes and invites ...

The Disability History Association has a podcast!

The Disability History Association Podcast was launched in early 2018 to provide a new and accessible medium for sharing and discussing disability history. Our monthly episodes feature interviews with people who are doing disability history both inside and outside the academic world, and full transcripts are available for every episode. The podcast is available on the DHA website **dishist.org** under the “Podcasts” link, and it is also widely promoted on social media. Please check it out and share it with your friends and colleagues to help more people learn about disability history and why it matters.

The sixteen episodes to date have featured topics like disability in the Waltons; reproductive and disability justice in California; the story of Oscar Moore, a blind African-American child prodigy; disability in Scotland, Canada, and Medieval Europe; and the collections at the Museum of the American Printing House for the Blind.

Do you have a story to tell? Do you want to share your experiences or discoveries in disability history with a broader audience, in a more accessible form?



We welcome community groups, activists, students, archivists, librarians, curators, scholars, and anyone else doing disability history to join us on the show. If you would like to be interviewed about your work, or if you are interested in guest hosting an episode or producing a podcast report from a conference or another disability history event, please contact me at **clieffers@gmail.com**.

For the upcoming year, we are especially interested in featuring disability history outside Europe and North America, community-based history and lived experiences of history, and work that connects disability history to ongoing issues of disability justice. However, all topics are and will continue to be welcome!

**From the DHA newsletter archives.** 'My Three Feet Dancing' by Alice Wexler first appeared in the Spring 2009 issue of the DHA Newsletter. It is reproduced here - both to re-air Wexler's discussion on experience of Huntington's Disease, and also as, hopefully, an inspiration to disability history scholars who might wish to consider ways in which they might like to contribute an essay or article to future editions.

## My Three Feet Dancing; or How I Came to Disability History

Alice Wexler, Research Scholar, UCLA Center for the Study of Women

I am tempted to say that I came to disability studies and disability history because I was instantly persuaded by the amazing books, articles, academic papers, and friends I encountered, starting in the 1990s. But in truth, my journey into disability history was a far more gradual process. While any account of intellectual change probably reveals more about the moment when it is written than about the events of the past, I nonetheless offer one possible narrative of my own venture into the land of disability history, where I have been exploring the territory, if not quite building a home.

As a historian who began graduate work in Latin American history in the late 1960s, taught the history of women in the US in the 1970s, and wrote a biography of the anarchist Emma Goldman in the 1980s, I was familiar both with comparative approaches to history and, more important, with feminist arguments about the importance of gender, race and class as inextricably linked categories of historical analysis. Disability as an analytical category made sense to me as a historian even if I did not always understand the radical ways that disability activists and scholars were starting to use it.

However the more immediate reason for my attraction to disability studies, and ultimately, to disability history, was my personal experience with Huntington's disease (HD), popularly called St. Vitus's dance, and once known within medicine as Huntington's chorea on account of the involuntary dancelike movements (chorea) that are its most characteristic symptom. I should note here that Huntington's differs markedly from those conditions that have been central to the disability rights movement and to disability studies. Unlike impairments such as blindness, deafness, or anatomical difference, Huntington's progresses inexorably toward total physical incapacity, dementia and death over ten to twenty years. Most people in the later stages of HD cannot operate a wheelchair, speak intelligibly, communicate via a computer, or use the assistive devices available to people with other kinds of impairments. Even in the early stages they often suffer psychiatric difficulties and loss of cognitive capacity leading to loss of employment and even conflicts with the

law. Huntington's is also one of a small group of severe conditions that is inherited as an autosomal (non-sex-linked) dominant disorder, meaning that each child of an affected parent runs a 50% risk of inheriting the variant gene. For many of those living with Huntington's, the knowledge that they may have unwittingly passed it on to their children and grandchildren produces almost unbearable guilt.

The symptoms are dramatic. Along with chorea, most people suffer personality changes, emotional disturbance, and cognitive decline. Typically starting in a person's thirties or forties (though it can begin much earlier or later), this disease, which has been reported in all races and ethnicities, affects some 30,000 people in the US, with about 150,000 more at 50% risk. [1]

For such a devastating condition, then, a medical model certainly seems appropriate. I would say that all members of the HD community want to see this disease wiped out, unlike members of the disability rights community who often feel that their disabled situation offers a valuable perspective from which to view the world. Many members of the HD community also use their situation in creative ways, but given the choice, no one that I know from a family with Huntington's, including my own, would choose this option for themselves or their children. Many feel that those who would choose suicide over living into the last, late stages of this disease ought to have this option.

And yet, over the past several years, as I came to know more families with the disease and attended more Huntington's meetings and workshops, I found myself struck by the extent to which members of affected families talked as much about the social and cultural dimensions of their suffering as about the more narrowly medical ones. Especially in the early stages, people living with Huntington's often seemed to feel more handicapped by social discrimination, isolation, and lack of modest assistance than by their choreic movements, a situation very much like that of people with other impairments. Almost all members of families with Huntington's, affected and unaffected alike, suffered from stigmatization and secrecy, the taboo against speaking of the disease even inside the family; from ill-informed and even prejudiced health professionals; being told they should not marry or have children; insurance discrimination. Those living with the disease often experienced the embarrassment of being stared at in public, or asked to leave a restaurant on account of disruptive movements. They suffered the loneliness of being unable to work and remaining at home with nothing to do, without personal assistance and usually the expectation that care would be performed by family members as unpaid labor. Almost always there was the near impossibility of finding appropriate long-term care for those in the advanced stages of the disease. Those who reported the least painful experiences with Huntington's often stressed their social support and access to services. [2]

In addition, because of its direct inheritance pattern, Huntington's seemed to stamp a kind of social identity on entire families, even though only a few members might actually have symptoms at any one time. HD advocates as well as health professionals referred to "Huntington's families," as if HD gave a special identity to everyone in that kinship, affected and unaffected alike, recalling the early twentieth-century eugenic discourse surrounding "defective," "degenerate," and "unfit" families.

In the summer of 1968, I learned for the first time that I belonged to one of those families. I learned that my fifty-three-year-old mother now had the dreaded symptoms that had killed her father, grandfather, and all of her brothers in their fifties, that my sister and I were at 50% risk of inheriting the same illness, and that if we did, we could pass on this disease to any children we might have.

Soon after my mother's diagnosis and the revelation of the family secret, my father plunged into the newly emerging world of Huntington's disease advocacy, followed a few years later by my sister, who became a Huntington's researcher herself. Excited by the recombinant DNA revolution of the 1970s and the advances in gene mapping of the 1980s, they, along with many others, were swept up in the optimism and excitement of "cutting edge science." Science was going to find "the cure" and not waste time and energy on halfway, palliative efforts. As a historian, I was attuned to thinking about the social dimensions of this scientific discourse, but I too got caught up in the romance of the gene. I wrote a book, *Mapping Fate: A Memoir of Family, Risk, and Genetic Research* (University of California Press, 1995), weaving together an account of recent genetic research on Huntington's with a more personal narrative about the familial impact of the disease.

Still, the process of researching and writing *Mapping Fate*, and especially the conversations and conferences that followed, opened up for me many questions being raised by disability studies scholars and activists. In some respects, I think I learned more after completing *Mapping Fate* than I did while writing it, at conferences and in conversations with other scholars and HD activists. [3] Many of the conferences I was invited to participate in addressed issues of disability in one way or another, often in relation to gender and to genetics--the focus of *Mapping Fate*--as seen through the lens of the social and cultural studies of science, technology, and medicine. Scholars such as Deborah Heath, Helen Longino, Jonathon Marks, Paul Miller, Paul Rabinow, Rayna Rapp, Tom Shakespeare, and Susan Squier opened my eyes to new questions about the cultural and social meanings of genes, genetics, and eugenics in relation to definitions of self and identity that were sometimes at odds with the perspectives prevailing within the Huntington's disease advocacy world. For instance, while voluntary personal choice emerged as the mantra within the HD community in the 1980s with respect to predictive genetic testing, the anthropologists and sociologists at these meetings took a more critical view of the rhetoric of "choice," emphasizing its economic and social limitations as well as its gendered and racial dimensions. And while people at risk for HD generally lauded PGD (Preimplantation Genetic Diagnosis) when it became available, seeing it as a way to have children who did not carry the variant gene even if they did themselves, scholars at these conferences raised questions about the cultural implications of technologies such as PGD, not only for people with disabilities but also for those who can know they carry genes for diseases that may emerge only late in life. These scholars pointed out that the new genetic technologies often had unanticipated consequences and complications--getting pregnant with *in vitro* fertilization, required for PGD, is not always possible, even for those who can afford its high cost--and were actually creating new categories of disability, such as the person who has tested positive for a disease that she will

develop later in life (like Huntington's) but as yet has no symptoms. *Mapping Fate* did address some of these issues, but as I look back on it now, I accepted too willingly the idea that having Huntington's--or finding out you were going to get it--was the worst catastrophe in the world, without considering more critically whether or when that was really the case, what made it so, and what might mitigate this outcome.

As a historian, of course, I also found myself thinking about the relevance of these perspectives for understanding the past. Eugenics, which haunted all these discussions, became another vehicle in which I traveled into the land of disability history. From the moment we found out about Huntington's in our family, I had wondered about my mother's secrecy. Why hadn't she told us her father died from Huntington's chorea, as it was then called? I can't recall just when I began to learn about the eugenics movement, but I know that as I learned more about it, I realized that my grandfather's death in 1929 coincided with the height of the organized eugenics movement in the United States, and that my mother had also come of age at that time, in the 1920s and 1930s. She had studied biology as an undergraduate at Hunter College, in New York, in the early 1930s, and had earned an M.A. in zoology soon after at Columbia University. Geneticists at that time studied *drosophila*; in the 1930s human genetics meant *eugenics*, which was considered a legitimate science despite growing criticisms from some geneticists. It occurred to me that the eugenics movement might explain a lot about my mother's secrecy. As Stephen Selden's book *Inheriting Shame* indicates, she almost certainly would have encountered eugenic ideas in her biology textbooks and college courses. [4] Undoubtedly she was familiar with the writing of the eminent biologist Charles B. Davenport, a leading North American eugenicist who had argued in favor of sterilizing people like her. As we know now, eugenics was a vastly popular social and scientific movement in the twentieth century U.S., and Huntington's disease, unlike "feeblemindedness," actually fit the Mendelian paradigm of inheritance embraced by many eugenicists.

My mother had never spoken to me about eugenics. But increasingly her shame and silence about Huntington's made sense in light of the eugenic milieu in which she grew up. Even critics of eugenics might have considered a woman like her a fitting subject for sterilization. I wanted to know more about how eugenic discourse affected my family, and other families as well. These were precisely the kind of questions that, by the mid-1990s, disability scholars as well as disability activists had begun to address.

Against this background, in the late 1990s I began the research that ended up as a book, *The Woman who Walked into the Sea: Huntington's and the Making of a Genetic Disease* (Yale University Press, 2008). I organized this book as three distinct but overlapping narratives, one of which dealt with the impact of early twentieth century eugenics on U.S. families associated with the disease, and another which explored how disparate behaviors came to be conceptualized, in the mid-nineteenth century, as a specific hereditary disease. But the dimension that most captured my imagination was the challenge of trying to recapture the lives of people who had lived and died with Huntington's (or what was often called St. Vitus's dance

or the magrums) in the late eighteenth and nineteenth centuries. I became obsessed with the desire to tell their stories, perhaps because they always appeared as shadows or ghosts haunting the medical literature on Huntington's. George Huntington had based his famous 1872 account of "hereditary chorea" on several families in East Hampton, New York, where he grew up, yet for reasons of confidentiality and medical convention, he did not name them, and left no published records of their identities. Despite the sparse evidence, I wanted to give them an historical presence and make them part of the narrative of Huntington's disease. (Ironically, this project was possible in part because of a eugenics field study that documented some of these old families.)

In fact, my research suggested that in nineteenth-century East Hampton, the local families associated with St. Vitus's dance were integrated and accepted in their community, even while their "weakness" was feared and "the subject was avoided by most people as distasteful." Although families with Huntington's appear to have been ostracized and shunned in certain other towns, in East Hampton that did not seem to be the case. East Hampton suggested that even so dramatic and severe a disease as Huntington's might be understood variously in different historical contexts, and that it did not necessarily lead to rejection. As I came to this conclusion, I saw parallels with Nora Groce's study of hereditary deafness on Martha's Vineyard, and began to think more about the relevance of a disability studies perspective for understanding Huntington's disease, and more broadly, the uses of Huntington's for conceptualizing disability. [5]

In short, Huntington's disease gave me a ground, a vantage point from which to enter the wider world of disability studies and disability history. In this sense, the experience of living within a Huntington's disease family and having a personal connection to what Paul Miller has called "the trauma of eugenics" became the starting point for exploring larger questions about how we define what is "normal" and "abnormal," and how such categories are used for political and cultural ends. Even if I remain personally committed to supporting efforts to find a cure for Huntington's, that commitment does not preclude a commitment to the broader goals of the disability rights movement, and to exploring the construction of disability historically within different temporal and cultural settings. Indeed, what is so exciting to me about disability studies is the radical challenge it poses to many of my own long-held assumptions about embodiment, suffering, and a meaningful life, in the past and in the present.

Having arrived at this point, how, then, do I look back upon my previous work that did not address either Huntington's disease or disability? Actually, I am surprised to see certain continuities between my recent projects and this earlier work. My first published articles in the 1970s argued that the predominantly white US soldiers and travelers to a multiracial Cuba in the nineteenth century constructed the Cubans according to racist stereotypes back home, in ways that flattered their own self-images and helped create subordinate subjects of imperialism. [6] The biography of the anarchist Emma Goldman that I wrote in the 1980s traced the life of a woman whose entire project was to agitate on behalf of the excluded and oppressed, and to work for a society without hierarchies based on economic, racial, gendered or sexual

differences. [7] These projects, it seems to me now, resonate with my later work on Huntington's, since they all, in one way or another, address the question of how dominant groups represented subordinate or excluded or stigmatized Others, and the ways in which these Others countered such representations: questions that also resonate with the concerns of disability studies and history today.

But I do not wish to impose too unifying a pattern on this disparate work. I do wish to note that while belonging to a family with Huntington's no doubt closed off some possibilities in my life, it also opened up others, in particular an embodied appreciation for the ways in which disability scholars today are reconceptualizing the meanings of bodies and embodiment, in the past well as in the present. Huntington's provided a jumping off point for a journey on which I have only just begun.

I think of myself now as having one foot in the social and cultural history of medicine, another foot in disability studies and history, and a third foot – or whatever it may be – in the Huntington's disease advocacy community, where I am active as a board member of the Hereditary Disease Foundation, an organization--headed by my sister Nancy Wexler--whose mission is finding a cure for the dancing disease of Huntington's. While each of my three feet often dances off in a direction of its own, throwing me off balance and even knocking me down from time to time, I enjoy the challenges and pleasures of this dance, and the new music and the movement that it demands.

#### Endnotes

1. See Gillian Bates, Peter Harper and Leslie Jones, eds., *Huntington's Disease*, 3rd ed. (Oxford University Press, 2002).
2. At an international meeting of patient advocacy groups a few years ago, I was startled to hear a woman from Belgium--a country with excellent health and social services--whose sister, brother, and father had had Huntington's--say that she had no complaints about the services available to them, and that the needs of her family were being met. I have never heard anyone say this in the United States.
3. See Paul E. Brodwin, ed. *Biotechnology and Culture: Bodies, Anxieties, Ethics* (Indiana University Press, 2000); *Empirical Bioethics in Cultural Context: Genetic Confidentiality, Ownership, and Public Participation in the United States and Japan* (Ithaca, N.Y.: Cornell University Dept. Science and Technology Studies, 2003); George Ellison, ed., *Diversity, Difference, and Deviance: Ethics in Human Biology* (Baker and Taylor, 2004); "Feminism Confronts Disability," UCLA, 2002.
4. Stephen Selden, *Inheriting Shame: The Story of Racism and Eugenics in America* (Teachers' College Press, 1999).
5. Nora Groce, *Everyone Here Spoke Sign Language: Hereditary Deafness on Martha's Vineyard* (Harvard University Press, 1985).



6. See "Pain and Prejudice in the Santiago Campaign of 1898," *Journal of Inter-American Studies and World Affairs* 18 (Feb. 1976), 59-73; "Sex, Race, and Character in 19th Century Accounts of Cuba," *Caribbean Studies* 18 (October 1978/January 1979), 115-30.

7. *Emma Goldman in America* (Beacon Press, 1984); *Emma Goldman in Exile* (Beacon Press, 1989).

## DHA Membership

Membership dues support the organization's activities and goal of promoting the study of the history of disability.

A one-year (January 1 to December 31) individual membership in the Disability History Association is thirty (\$30 U.S.) dollars. We offer a student/low or fixed income membership of fifteen (\$15 U.S.) dollars per year. The DHA also offers institutional memberships at the rate of one hundred (\$100 U.S.) dollars per year (see below), and lifetime memberships for five hundred (\$500) dollars. If you are a U.S. citizen, your dues are tax deductible.

To join the Disability History Association, please fill out the form under Membership on the website. Dues may be paid through PayPal.com, or you may send a check or money order (made payable to the Disability History Association) to the address below. When you submit the form you will be transferred to <http://www.paypal.com> where you can pay online. If you would prefer, you can simply submit your information and send a check or money order to our Treasurer, Kathleen Brian:

Kathleen Brian  
22809 Lakeview Dr. #E406  
Mountlake Terrace, WA 98043

We respect your privacy and will keep the information you provide confidential.

For questions about membership and dues, please contact Kathleen Brian, DHA Treasurer, at [disability.history@gmail.com](mailto:disability.history@gmail.com).

## DHA News

We hope that you have enjoyed reading this newsletter. How about writing for the next one? Short articles or story pieces. New research projects. Letters to the Editor. Finds in the Archive, such as unusual pieces of disability history that you have discovered in unusual places. Photos and other visual material – with the usual permissions and credits where applicable.

Or just drop an email to say 'Hi!' – to Iain: [iain.hutchison@glasgow.ac.uk](mailto:iain.hutchison@glasgow.ac.uk)