

Spring 2017 DHA Newsletter

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MESSAGE FROM THE RETIRING EDITOR

Penny L. Richards

WELCOME!

Yes, retiring editor. I've been editing the DHA Newsletter since 2009 (Cathy Kudlick had this job before me). That's eight years, fifteen issues I think? Always fun to compile, honestly! I'm just needing more time away from keyboards and laptops and emails, as life's other responsibilities grow and change.

Thanks for all the kind words in private and public spaces, and all the best to all the DHA members in all your various future pursuits.

Penny

If you have a moment, would you contact DHA President Sandy Sufian at (sufians@uic.edu) and let DHA know if you have any suggestions for improvements, especially with regard to activities or programs? The DHA Board of Directors are striving to find new ways to promote disability history and would be very appreciative of your feedback.

Have you renewed your DHA membership for 2017? Please consider doing that right now, while you're enjoying the newsletter, it won't take but a moment. And if you already have your membership, perhaps make a surprise gift to a colleague or student?

http://dishist.org/?page_id=25

Did you know that the DHA is now on Facebook?

The Disability History Association recently set up a public Facebook page telling its social media audience about the organization and posting updates on scholarships, conferences, lectures and more. It has also set up a closed Facebook group for its members to join that will act as a way for DHA members to exchange their work, post queries, and give individual updates and announcements. For members, please search for Disability History Association in the facebook search bar and then request to join this group.

<https://www.facebook.com/groups/disabilityhistoryassociation/> (closed group)

<https://www.facebook.com/DisabilityHistory/>

MESSAGE FROM THE DHA PRESIDENT

Sandy Sufian

Dear DHA Members:

It is with a mixture of happiness and sadness to have this be Penny Richards' last newsletter for the DHA; happiness because she is embarking upon her retirement and a chance to pursue other dreams and time with family, and sadness because Penny has contributed so much to our disability history community and to the DHA in particular.

Penny has served as editor of our newsletter for as long as I can remember, allowing communication between the organization and our members to grow and deepen. She has kept us updated on upcoming conferences, panels, papers, exhibits and podcasts, award winners, member publications, membership renewals, and various pieces on disability history. Penny has provided us with rich resources to explore so many topics of and periods in disability history, thereby helping us to continue to expand the reach of our ever-growing field.

In addition to her editorship of our newsletter, Penny has served as editor of H-Disability and as president of the DHA. For years, she has compiled the treasured monthly bibliography in disability history that so many of us rely upon for our teaching and scholarship. Her own scholarship on nineteenth-century American experiences of disability and family-life, history of education, disability and immigration, and other topics has added to our understanding of how people with disabilities experienced their worlds in complicated ways.

We will miss Penny, her positivity and fun-loving nature. We thank her for her years of service to this field.

Thank you Penny, from the bottom of our hearts.

On Behalf of the DHA Board,

Sandy Sufian
President, Disability History Association

ANNOUNCEMENTS

Disability History Association Seeks Members for Several Positions

The Disability History Association (DHA) is an international, nonprofit organization dedicated to the historical study and teaching of disability across all time periods and contexts. The DHA offers its members a community of active and interesting historians building a vibrant field of study. Members also enjoy access to our resources page, which includes our newsletters, conference information, and sample syllabi.

The Disability History Association seeks **members** for several different positions:

1. VP for Communications to serve on the DHA Board
2. Graduate student representative to serve on the DHA Board
3. Three H-Disability Advisory Board members

VP for Communications

The VP for Communications (rank of faculty) will oversee the communications strategy and will supervise the communications intern. This person will also be a voting member of the DHA Board. Responsibilities include: serving as a liaison between the Board and the intern, making sure our FB page is updated by the intern, ensuring our FB group grows and is active, ensuring our website is up to date and that the intern uploads syllabi and newsletters as well as posts upcoming conferences and other information.

This position has a three-year term, with an option to extend or renew the term.

Graduate Student Representative

The Graduate Student Representative serves on the Board and participates fully in all meetings, discussions and votes. The Graduate Student Representative serves as the liaison between the DHA Board and its graduate student members, offering a student voice to our direction and goals.

This position has a three-year term, with an option to extend or renew the term.

H-Disability Advisory Board members: three

We are seeking three DHA members to serve as advisory board members for H-Disability, the international history of disability listserv. The Advisory Board members will help the H-Disability editors identify any desirable developments and/or additions in content. According to H-Net (within which H-Disability functions) other responsibilities for advisory board members may include:

- Assisting in the peer-reviewing process and the development of multimedia content by assisting editors in making policies for the network.
- Reviewing disputes brought to their attention by the network or review editors.
- Serving as “ambassadors” for their network by joining discussions, helping to recruit new editors and board members, developing new threads, and serving as liaisons to professional organizations (between H-Disability and DHA).

For further inquiries into these positions, please email Kathleen Brian, kathleen.brian@wwu.edu.

This position has a two-year term, with an option to extend or renew the term.

To apply, please send a brief letter of approximately 200-400 words explaining your interest and skills for the respective position. Please send an email of interest to: Sandy Sufian, President, DHA at sufians@uic.edu.

Disability History Association Communications Internship

The Disability History Association (DHA) seeks a volunteer, part-time communications intern. The intern will assist with updating and making our organization’s website fully accessible as well as creating and monitoring a social media presence. All qualified individuals are welcome to apply, including undergraduate students. Familiarity with disability communities and disability history is a plus. This volunteer internship offers an excellent opportunity to develop web-based communication skills, to learn more about disability history as a field of study, and to connect with our broad community. Mentorship in pursuing disability history work is also available. This internship has flexible hours and scope of work. For example, an intern could work on projects for 2-4

hours a week, or for more hours across a month. Duration of internship negotiable, but we are seeking a minimum of three (3) months commitment, preferably more.

The Disability History Association is an international, nonprofit organization dedicated to the historical study and teaching of disability across all time periods and contexts. The DHA offers its members a community of active and interesting historians building a vibrant field of study. Members also enjoy access to our resources page, which includes our newsletters, conference information, and sample syllabi.

Responsibilities:

- *Assistance with updating our website and making it accessible to all types of users.
- *Creating, updating and monitoring Facebook and Twitter accounts
- *Assistance with a longer-term social media plan
- *Ongoing collection and posting of syllabi on our website
- *Advertising our presence at various conferences

Qualifications:

- *Previous experience in the areas of journalism, marketing, communications, public relations, or a related field.
- *Computer skills to perform website updates, post new material and create graphics and new links
- *Interest in or knowledge of disability studies or disability history
- *Proficient English-language writing skills

To apply, please send a brief letter of approximately 200-400 words explaining your related skills for this internship. Please also include what goals you have for the internship and how this work fits into your career pursuits, personal interests or volunteer service. A resume or list of relevant work/internship/academic experience should be included as well. We encourage you to provide the name and contact information for at least one reference (someone who is familiar with you and your work).

Please send this letter to Sandy Sufian, President, DHA at sufians@uic.edu.

“Patient No More” Exhibit at San Francisco Public Library Cathy Kudlick

The Paul K. Longmore Institute on Disability at San Francisco State University’s exhibit “Patient No More: People with Disabilities Securing Civil Rights” will be up at San Francisco Public Library, 100 Larkin Street 6th floor, from June 10-September 3. This interactive exhibit with innovative (and subversive!) access features is open during

regular library hours. There will be a launch event on June 10 from 1-3pm in the Koret Auditorium. For more information visit: <https://sites7.sfsu.edu/longmoreinstitute/patient-no-more>

Disability History at 2017 American History of Education Society meeting Kate Rousmaniere

#1. This panel below will be presented at the American History of Education Society annual meeting Thursday, November 2 through Sunday, November 5, 2017 at the Little Rock Marriott Hotel in historic Little Rock, Arkansas. Contact Kate Rousmaniere for more information rousmak@miamioh.edu

New Research in the History of Disabilities and Education

"Growing Special Education in Wisconsin: Origins of a Unique Teaching Profession"
Robert Osgood, St. Norbert College

"One of the Greatest Problems of Our Educational Program:" Scientific Studies on
Teacher Mental Health and Maladjustment
Kristen Chmielewski, University of Iowa

Accessible Educators: The Case of Judith Heumann, New York, 1970
Kate Rousmaniere, Miami University, Ohio

Chair and Discussant: Jason Ellis, University of British Columbia

New Research in the History of Disabilities and Education

This session introduces current research in the history of disabilities in education and in the history of special education. While the history of special education has existed for some time (Tropea, 1987; Osgood 1997, 2005, 2008) and continues to be vibrant (Ellis, 2013; Ellis and Axelrod, 2016) the introduction of a critical disabilities construct into the history of education has developed only recently, drawing on new historical studies in disability (Kudlick, 2003; Verstraete, 2012; Baynton, 2013). The founding of the Disability History Association in the 1990s has furthered the integration of disability studies into historical research broadly, and the history of education specifically, as noted in Kate Rousmaniere's 2013 *History of Education Quarterly* essay, "Those who can't, teach: The Disabling History of American Educators," (Rousmaniere, 2013). As Rousmaniere explains, the incorporation of an analytical framework of disability studies allows historians of education "to see *first*, how educational systems, practices, values, and professional norms have developed in a way that excludes people with disabilities from educational employment, or assigned them to parallel and marginalized

institutions of special education and *second*, how notions of normality have defined the work and identity of all educators.” (Rousmaniere, 2013, p. 90)

This session introduces work in the disability history of education by bringing together two senior scholars and two junior scholars who are all engaged in the study of disabling practices in the history of education: specifically in the development of special education practices and norms in teacher education, the adoption of mental hygiene practices in the recruitment, evaluation and professional definition of teachers, and a biographical snapshot of one of the first teacher disability activists. Our discussant is a well known scholar in the history of disability in education and special education in North America.

Disability history paper wins ISCHE award

Kate Rousmaniere

Kristen Chmielewski, doctoral student at the University of Iowa won the early career conference paper award from ISCHE (International Standing Conference on the History of Education) for her paper that was presented at the 2016 annual meeting in Chicago: “‘Hopelessly Insane, Some Almost Maniac:’ New York City’s War on ‘Unfit’ Teachers” as the winner. The paper will be included in the special conference issue of *Paedagogica Historica*, to be published in Spring 2018, and will be announced at the General Assembly of ISCHE in Buenos Aires this summer.

CALLS FOR PAPERS

CFP: THE FORGOTTEN OTHER: DISABILITY STUDIES AND THE CLASSICAL BODY

An interdisciplinary conference to be held at Kings College London, 18th–19th June 2018
<https://effacedblog.wordpress.com/2017/03/31/cfp-disability-studies-and-the-classical-body/>

Organisers:

Ellen Adams (Lecturer in Classical Art and Archaeology, Kings College London)
Emma-Jayne Graham (Senior Lecturer in Classical Studies, The Open University)

The influence of the classical bodily ideal on Western notions of beauty has been vast. But what of the broken body, as so many classical marble sculptures have become? While philosophical explorations of the body and the senses may reference the ancient world as a starting point, there is generally little engagement with the sensory body that is impaired or progressively failing. If we are interested in the body, past or present, experienced or represented, we must look to what happens when it ‘breaks’ – the challenges posed and met, the hurdles overcome or un-surmounted, and the remarkable strategies adopted to mitigate any disabling effects of physical and sensory impairments – by both individuals and their societies. Studying the disabled in the ancient past has yet to engage with Disability Studies in a way comparable with other areas of identity politics, such as gender, sexuality and race. Classics, and its cognate disciplines, has nevertheless played a role in shaping the modern concepts of impairment and disability that form the basis of contemporary Disability Studies, and this relationship deserves further exploration.

This conference seeks to explore shared ground by examining what modern debates concerning impairments and disabilities can add to our understanding of ancient bodies and identities. It will question why ‘non-normative’ bodies are so rarely brought into the mix by classicists, historians and archaeologists studying ancient social and cultural contexts, and how doing so can offer suggestive new ways of understanding the complex relationship between bodies, identities and divergent experiences of the world.

We invite papers which explore these issues from the standpoint of both Classical Studies and Disability Studies (of all periods). Plenty of time will be dedicated to discussion and, where possible, the organisers hope to ‘pair up’ speakers from different disciplinary backgrounds in order to encourage greater reflection on the synergies and differences of each approach. Free-standing papers will also be welcomed. Topics might include, but are not limited to:

- The ableism inherent in the Humanities
- Reference to the classical world and ancient thinkers in Disability Studies

- ‘Fixing’ impairments (including aids)
- The tension between ‘disabled’ and ‘unable’
- The terminology of disabilities
- Moving beyond etic objectification to the emic voice of the (impaired) person
- The application of social, medical and interactional models to the classical world
- Other approaches to treating disabilities (e.g. ritual)
- The phenomenology of impairment, including movement and kinaesthesia
- Sensory impairment and embodied experience
- The disabled ‘beautiful body’ and the beautiful disabled body
- Experiences of and attitudes towards progressive disabilities and sensory impairments.

Confirmed speakers include: Patty Baker, Eleanor Betts, Lennard Davis, Jane Draycott, Edith Hall, Brian Hurwitz, Helen King, Christian Laes, Michiel Meeusen, Georgia Petridou, Tom Shakespeare, Michael Squire, Hannah Thompson.

Papers should be 20 minutes in length and abstracts of approximately 200-300 words should be submitted to either Ellen Adams (Ellen.Adams@kcl.ac.uk) or Emma-Jayne Graham (Emma-jayne.graham@open.ac.uk) by 31st July 2017. Successful contributions may be considered for publication in a conference volume. Funding may be available to support travel and accommodation for speakers where necessary.

**CFP: STORIES OF ILLNESS/DISABILITY IN LITERATURE AND COMICS
(Berlin, 27-28 October 2017)**

<http://centreformedicalhumanities.org/stories-of-illnesdisability-in-literature-and-comics-cfp-berlin-october-27-28-2017/>

The PathoGraphics research team at the Freie Universität Berlin, Germany announces this two-day academic conference and call for papers: ‘Stories of Illness/Disability in Literature and Comics. Intersections of the Medical, the Personal, and the Cultural’. The keynote speaker will be Leigh Gilmore (Wellesley College), author of *The Limits of Autobiography: Trauma and Testimony* and *Tainted Witness: Why we doubt what women say about their lives*.

The conference will examine the ways in which knowledge and experience of illness and disability circulate within the realms of medicine, art, the personal and the cultural. We invite

papers that address this question from a variety of different perspectives, including literary scholarship, comics studies, media studies, disability studies, and health humanities/sociology/geography.

To launch this conference, there will be an exhibit of comics dealing with medicine, illness/disability, and caregiving, presented in the permanent pathological collection of Berlin's Museum of Medical History at the Charité established by Rudolf Virchow. The museum's anonymous anatomical specimens will be juxtaposed with situated personal works of comic art.

The exhibition, which runs for three months, opens Thursday 26 October 2017 with talks by two of the central figures of the graphic medicine movement: MK Czerwiec, nurse and author of the comic *Taking Turns. Stories from HIV/AIDS Care Unit 371*, and Ian Williams, physician and author of the comic *The Bad Doctor. The Troubled Life and Times of Dr. Iwan James*.

For the conference that follows, we invite as yet unpublished papers on comics and/or literary texts (both fictional and autobiographical) addressing one (or more) of the following questions:

• Shared Spaces: The Transformative Relations between Literature/Comics and Medicine/Science

How do scientific/medical professionals use comics and/or literature to engage the public and impart new research or public health measures? How do narrative and graphic illness stories influence medical and scientific concepts of health and disease? How do these diverse spaces of experience and knowledge interact with each other?

• Inner Landscapes: The Aesthetics of Representing the Lived Experience of Illness

What aesthetic strategies do literary works and comics use to reveal the inner perspective of living with illness/disability/medical treatment? How do narratives represent emotional situations of invisible suffering, such as psychic disorders, trauma, involuntary memories and flashbacks, but also autoimmune diseases or cancer? Literature has developed aesthetic techniques such as inner monologue, stream of consciousness, and metaphors; do comics employ comparable or different aesthetic strategies?

• Timelines, Time Spirals, Time Vectors: Communicating Acute Illness, Chronic Disease, and Terminal Illness

In *On Being Ill*, Virginia Woolf characterizes periods of illness as having a time of their own, "slowing down" life, revealing humans' finiteness and inspiring unprecedented creativity. How do other literary and graphic illness narratives reflect the perception of time during illness? How is the disruption of acute illness or the caesura brought on by a new diagnosis represented? Do comics and literature employ different means of representing life with a chronic condition?

• Confessing, Surviving, Normalizing: Constructing the Self in Illness Narratives

What kind of subject is produced in contemporary illness narratives that rely on the confessional mode? As Michel Foucault has argued, such a mode is double-edged: it presumes a powerful speaking subject who is simultaneously subjected to the very institutions s/he addresses, ranging from healthcare to patient support groups and including the audiences of illness narratives. What kind of identity is enabled or foreclosed by concepts such as “survivorship”? What avatars are created in illness comics – do they differ from protagonists in written texts? Do literature and comics take part in or go beyond a process of normalization that is entailed in the confessional mode and the term ‘compliant patient’?

• **The Politics of Storying Illness: Going beyond the Individual**

Can illness narratives give voice to the experience of entire communities or comment on national healthcare systems (and their potential flaws)? Are there texts and comics that offer alternatives to narratives that focus on a single protagonist – if so, how do they do it? To what extent are illness narratives in literature and comics emancipatory and subversive, and to what extent do they tie into contemporary endeavors in bio-medical self-management, prophylaxis, and prevention?

For each panel, we welcome either theoretical reflections on or close readings of literary texts and/or comics; comparative papers on both artistic media are especially welcome. Accepted participants will receive funding to cover travel and accommodation expenses. Selected papers will be considered for publication in an edited volume on the subject of patho/graphics, i.e. literature and comics on illness/disability.

Paper proposals should include a title, a 300-word abstract (max) for a 20-minute presentation, and a short biographical note with institutional affiliation (where appropriate). Abstracts and papers can be in either English or German. Please submit by email by 31 May 2017.

Prof. Dr. Irmela Marei Krüger-Fürhoff (Berlin) and Prof. Susan Merrill Squier, PhD (Penn State), PathoGraphics research project, Friedrich Schlegel School of Literary Studies, Freie Universität Berlin, Habelschwerdter Allee 45, 14195 Berlin, Germany. This conference is made possible by: Einstein Foundation Berlin, Friedrich Schlegel Graduate School of Literary Studies, Freie Universität Berlin.

UPCOMING CONFERENCES

25-27 May 2017, Denton TX USA

Conference: **Monstrous Women in Comics**

<http://monstrouswomen.blogspot.com>

6-7 June 2017, London UK

Conference: **VariAbilities III: The Same Only Different?**

<https://effacedblog.wordpress.com/2016/08/30/cfp-variabilities-iii/>

14-16 June 2017, Milan ITALY

Conference: **First International Conference on Historical Medical Discourse**

<http://www.disabilitystudiesnetwork.gla.ac.uk/2017/01/22/cfp-first-international-conference-on-historical-medical-discourse-milan/>

23 June 2017, London UK

Conference: **Different Bodies: (Self-)Representation, Disability and the Media**

<http://commlist.org/archive/all/2017-all/msg00353.html>

5-6 July 2017, Liverpool UK

Conference: **Disability and Disciplines: The International Conference on Educational, Cultural, and Disability Studies**

<https://www.facebook.com/DisciplinesConference>

27-28 October 2017, Berlin GERMANY

Conference: **Stories of Illness/Disability in Literature and Comics**

<http://centreformedicalhumanities.org/stories-of-illnesdisability-in-literature-and-comics-cfp-berlin-october-27-28-2017/>

18-19 June 2018, London UK

Conference: **The Forgotten Other: Disability Studies and the Classical Body**

<https://effacedblog.wordpress.com/2017/03/31/cfp-disability-studies-and-the-classical-body/>

H-Disability Reviews

Iain Hutchison

H-Net (Humanities and Social Sciences Online) embraces a wide range of interest areas within the humanities. In the wider scheme of things, the history of disability might be viewed as a relatively new discipline, and indeed quite a specialist area. Disability history has certainly developed a notable vibrancy during the last couple of decades, but it is actually quite a broad area of enquiry, not just in the great diversity of situations and interpretations that constitute disability, but in the way that impairment is not only among us and our families, but is a part of us. Very few of us will escape disability during our life courses. So disability history is really for everyone.

The extent to which the history of disability has burgeoned as a discipline can be seen in burgeoning scholarly output of journal articles, edited collections and monographs. H-Disability Reviews was relaunched at the end of 2009 and since then reviews have been published for over 160 titles. Of the various groups that operate under the H-Net umbrella, over 150 are currently active in publishing reviews of works related to their discipline. At the time of writing, H-Disability sits at 28th in the rankings in terms of titles reviewed in the last twelve months. So, thank you to our reviewers for ensuring disability historians' work is attaining this level of exposure, not just on H-Net, but in the wider dissemination that follows.

There is of course always more that we can achieve. While reviews are published in English, titles reviewed include other languages. This something that we would like to expand, not only to engage with historical research being conducted in countries where English is not the first language, but to engage with disability history beyond both the anglophone world and the dominant Europe/North America axis. Recent examples of works focusing beyond that axis include Sarah Pinto's *Daughters of Parvati: Women and Madness in Contemporary India* (University of Pennsylvania Press, 2014) reviewed by Esme Cleall; and, not a book but a film, *Body and Soul / De Corpo e Alma* (Third World Newsreel, 2011) set in Mozambique and reviewed by Lyusyena Kirakosyan.

Our reviewers adopt their own styles of reviewing. Some choose to appraise books chapter by chapter, some build their reviews around significant quotations from the text, and some home in on themes for analytical evaluation. Of course H-Disability reviews are published online and this brings two benefits over hardcopy publication. One is that there is no word limit – while most reviews average from 800 to 1,200 words, some of our reviewers appreciate the lack of word constraint and we have had some exceptionally comprehensive reviews that have exceeded 4,000 words in length. The second advantage is that once reviews have been edited, copyedited and any queries addressed, they can be published instantaneously. So there is not a long wait for your review to be published.

The H-Disability reviews facility serves authors, publishers, and the reviewers themselves. We operate a fairly generous time period for the completion of reviews – of about six months. This is intended to acknowledge that reviewers often have demanding teaching and research schedules, but also recognises that many disability historians have impairing circumstances themselves and need a reasonable time allotment to complete an assignment. Indeed, the allotted time is periodically exceeded, sometimes quite substantially, but accommodation is willingly negotiated, our only request being that reviewers keep us apprised of their needs.

We are always keen to expand our pool of reliable reviewers. So, if you would like to review for H-Disability, please get in touch, telling us a bit about yourself, your affiliation, your areas and time periods of interest and expertise, and if you are able to review books in languages additional to English. If you have recently published a monograph or edited collection, and would like it to be reviewed by H-Disability, please also get in touch – and mention H-Disability to your publishing house.

Dr Iain Hutchison, Centre for the History of Medicine, Lilybank House, University of Glasgow, Glasgow G12 8RT, Scotland. Email: iain.hutchison@glasgow.ac.uk

Rest in Peace, Charles Byrne, the Irish Giant? A Last Testament from the Eighteenth Century

David A. Gerber
University at Buffalo

It isn't often that the deathbed wishes of an obscure eighteenth century Irish peasant who barely lived 22 years become a matter for contemporary public ethical debate and, through a segment of *All Things Considered* in March of 2017, national popular media attention.¹ Such is the case, however, with the instructions that Charles Byrne, who became known during his brief life as “the Irish Giant,” gave his friends as he lay dying in shabby rooms in London in 1783. Byrne told them that he desired to be buried at sea in a leaded coffin that would sink irretrievably to the ocean floor, there to be left alone forever.² Byrne is still waiting to have his deathbed wishes honored.

I have used the word “obscure” to refer to Byrne, but Byrne’s obscurity is true in one significant way, but not in another. That is, the public man was well known, but not the private man. In his own time, Byrne briefly gained notoriety in Ireland and in

¹ A transcript of the story of Charles Byrne, which aired in March 13, 2007 on NPR’s *All Things Considered*, can be found at Nell Greenfield Boyce, “The Saga of the Irish Giant’s Bones Dismays Medical Ethicists,” <http://www.npr.org/sections/health-shots/2017/03/13/514117230/the-saga-of-the-irish-giants-bones-dismays-medical-ethicists> (accessed May 11, 2017).

² A brief but convenient, well-documented narrative of Byrne’s life, deathbed wishes, and posthumous fate is found at Eric Cabbage, “The Tragic Story of Charles Byrne, ‘The Irish Giant,’” www.thetallestman.com/pdf/charlesbyrne.pdf (accessed March 14, 2017). *The Wikipedia* essay is shorter, but also well-documented and up-to-date to 2015; at [https://en.wikipedia.org/wiki/Charles_Byrne_\(giant\)](https://en.wikipedia.org/wiki/Charles_Byrne_(giant)) (accessed March 14, 2017). For a remarkably parallel story – another Irish giant terrified of falling into the hands of grave robbers and anatomists after death and used for display and research, see G. Frankcom and J.H. Musgrave, *The Irish Giant: Life of Patrick Cotter O’Brien* (London: Duckworth and Co., Ltd., 1976). O’Brien succeeded where Byrne failed: he was buried in deep, well-protected grave, and his remains were not stolen from his coffin.

England. Suffering from acromegaly, at somewhere probably around 7 feet 7 inches tall (although described in his time, probably for marketing purposes, as tall as 8 feet 4 inches), Byrne was no ordinary man. He is said to have lit his pipe while walking through the city by leaning over to the flame of the street gas lamps. Decades before the proliferation of carnival freak shows, for a year or two before his untimely death from the effects both of the pituitary gland tumor that accounted for his great height and of excess alcohol consumption, he allowed himself to be displayed for money in London. Thereafter, in spite of his deathbed wishes about the disposition of his remains, he remained posthumously, and is to this day, an exhibit. Through circumstances that point to betrayal by one or more of the friends who were supposed to have buried him at sea, Byrne's corpse ended up in the possession of John Hunter, one of the era's most eminent surgeons and anatomical researchers. Hunter was then known for maintaining a private museum for the display of the remains of human and animal oddities. Hunter also practiced a kind of empirical medicine, based not on theories and accumulated wisdom of the sort found in textbooks, but on autopsies of cadavers, gathered it appears from random sources of the sort that lent themselves to the horror classic, *The Body Snatcher* (1945). Around Hunter, in fact, swirled rumors of grave robbing, a not uncommon suspicion attached to surgeons and anatomists for many decades in Britain and in the United States.³

³ Based on a short story of the same title by Robert Louis Stevenson that was published in 1884 in the Pall Mall Gazette, *The Body Snatcher* was not inspired by Hunter's story, but by the confessions of one William Burke, a Scottish grave robber and murderer from earlier in the century whose story, as urban legend, Stevenson heard from his neighbors in a Scottish village; at <http://medhum.med.nyu.edu/view/296> (accessed April 18, 2017). There was no need to limit oneself to oral traditions in gaining perspectives on the phenomenon: grave robbing was widespread and well documented in the nineteenth century, see, for example, Suzanne M. Schultz, *Body Snatching: The Robbing of Graves for the Education of Physicians in Early Nineteenth Century America* (Jefferson, N.C.: McFarland, 2005); and on William Burke and his compatriots and their world, R. Michael Gordon, *The Infamous Burke and Hare: Serial Killers and Resurrectionists of Nineteenth Century Edinburgh* (Jefferson, N.C.: McFarland, 2009).

Hunter's collection would eventually become a source of public enlightenment. It was originally to be viewed in a house museum, but is now the historical core of the acclaimed Hunterian Museum at the Royal College of Surgeons in London. A central, boldly and well illuminated part of the exhibit of what Hunter bequeathed to posterity is the display of Charles Byrne's massive skeleton, which has been on view for over two centuries to the wonderment of visitors, who are made aware of Byrne's identity and his sadly short and apparently troubled life.⁴

The basic facts of his biographical narrative related above as well as the how and the why, and at the direction of whom, Byrne came to be betrayed and his remains displayed are known well enough. But much more obscure is what Byrne thought about living in a situation of unique isolation, with a medical condition that was both the source of his brief encounter with notoriety and moneymaking and a cause of great pain and early death. Like most individuals we have come, much too casually, to call "freaks," others spoke, mostly in hyped up terms, for him, while seeking to take advantage of his condition to make themselves a pile of money. In fact, other than general reports about his genial, gentlemanly conversation with those Londoners who paid to view him in private rented rooms, his deathbed wishes are about the most we know of what Byrne had to say about anything. What those wishes seem to say about Byrne is that whatever he might do in displaying his body to make money, Byrne ultimately would insist that he

⁴ On John Hunter, see, Wendy Moore, *The Knife Man –The Extraordinary Life and Times of John Hunter, Father of Modern Surgery* (New York: Broadway Books, 2005); John Kobler, *The Reluctant Surgeon: The Life of John Hunter* (London: Heinemann, 1960). On the London Hunterian Museum, see, Samuel J.M.M. Alberti, *Hunterian Museum at the Royal College of Surgeons Guidebook* (London: Royal College of Surgeons of England, 2011).

A portrait of John Hunter in a contemplative pose, done in 1787 by the renowned Sir Joshua Reynolds, has a bottom portion of Byrne's skeletal legs dangling in the shadows in its upper right hand corner, as if perhaps to make a statement.

be accorded human dignity. He had his dignity, and apparently control of his body, including its representation, was an integral part of his conception of that dignity.

Twenty-five years ago, I began a brief debate with the eminent disability scholar Robert Bogdan about the moral legitimacy of freak shows and the public display of people, such as giants, dwarfs, the legless and the armless, microcephalics, conjoined twins, and others with rare physical anomalies. Professor Bogdan had just published his path-breaking and well regarded historical work, *Freak Show*. In it, Bogdan sought to move our understanding of freaks beyond the moralized and medicalized discourses that had led in the mid-twentieth century to the near-complete banning of freak shows, whether by law or by a sort of public enlightenment that destroyed the enthusiasm of their potential audience. For Bogdan, freaks were just different looking human beings who became show business acts that canny promoters advanced at carnivals. No one was really a *freak* as such; *freak* was a social construct that was a product of marketing. Those displayed were in on what was more or less a scam, and used their display to make a mostly innocent buck off the credulity of an audience full of suckers. My position was that those displayed had little choice in the matter of the means they embraced for their survival, because by and large there was no other way for them to make a living. Moreover, many freaks had been channeled in that direction from childhood by their parents, who fell under the sway of entertainment promoters (which was the course of Charles Byrne's own life). To be a freak, I maintained, was to bear the stigma carried historically by most people with disabilities, and hence at some level to have one's dignity assaulted. For me, that stigma was a source of oppression that was superficially masked in the case of the freak show as opportunity. Below the surface of

consent or compliance, I argued, where rarely here and there, as in the case of Tom Thumb we could probe more deeply, we find evidence of ambivalence about being displayed as a livelihood and as a way of life.⁵

To my surprise, and perhaps Bogdan's too, paired together in some array, *Freak Show* (or selections from it, or further remarks based on it), my own 1992 article in the British journal *Disability, Handicap and Society* examining the moral assumptions of his book from the position of the powerlessness and oppression of people with disabilities in the historical past, and our brief exchange of contrasting views in the pages of the same journal in 1993 has become a classic debate within Disability Studies.⁶ This confrontation of radically different views of the same phenomenon has been used by instructors for much longer than most scholarly disagreements are found to be relevant, to open the minds of students to the psychological, cultural, and moral foundations of disability representation, and hence to awaken them to the politics of representation. It is not merely a legitimate conflict of opinions that invites us quickly to move beyond it, but the type of disagreement that seems to have lasting instructive value in examining first principles and foundational assumptions. As such, it helped in some small measure to get Disability Studies off the ground and into a self-reflective

⁵ Robert Bogdan, *Freak Show: Presenting Human Oddities for Amusement and Profit* (Chicago: University of Chicago Press, 1988); David A. Gerber, "Volition and Valorization in the Analysis of the 'Careers' of People Exhibited in Freak Shows," *Disability, Handicap, and Society*, 7, n.1 (1992), 53-69; Robert Bogdan, "In Defense of *Freak Show*," *Disability, Handicap, and Society*, 8, n.1 (1993), 91-94; David A. Gerber, "Interpreting the Freak Show and *Freak Show*," *Disability, Handicap, and Society*, 8, n.4 (1993), 435-436.

⁶ The presentation of these opposing views as a foundational debate examining disciplinary assumptions began in Rosemarie Garland Thompson, *Freakery: Cultural Spectacles of the Extraordinary Body* (New York: New York University Press, 1996), with the paired presentation of an essay by Bogdan and by Gerber.

disciplinary posture. For that reason, I am very pleased to have helped to stimulate that discussion, and hope that Robert Bogdan has shared that pleasure.

Recent developments in Charles Byrne's still unfolding story reopen both this debate and the longer-standing issue of Byrne's last wishes. Hunter could not have known either the proximate or the genetic cause of Byrne's great height, but asked to defend possession of the Irish giant's skeleton against what soon became known as Byrne's expressed wishes, he and others after him stated that the skeleton somehow advanced medical science and its display had instructive purposes for general public. That medical advancement was actually slow and very uneven in coming. Well over a century after Byrne's death, in 1909, the pioneer American neurosurgeon Harvey Cushing of Johns Hopkins University determined after examining Byrne's skeleton that he suffered from a pituitary gland tumor, which caused his great height. In 1915 Cushing would perform an operation that demonstrated the influence of pituitary malfunctioning on human height. Another century later, in an era of advanced genetics research, British and German investigators announced in 2011, after retrieving DNA from Byrne's teeth, that the presence of that tumor resulted from a very rare genetic mutation.⁷

The facts of his condition finally understood, it could no longer be argued that somehow Byrne's skeleton served anticipatable scientific purposes. Medical ethicists

⁷Cushing's path breaking research on disorders of the pituitary gland, including acromegaly, is analyzed in Michael Bliss, *Harvey Cushing: A Life in Surgery* (New York: Oxford University Press, 2005), pp.204-246. On recent genetic research using Byrne's DNA, see, Havinder S. Chahal, et al., "Brief Report. *AIP* Mutation in Pituitary Adenomas in the Eighteenth Century and Today," *New England Journal of Medicine*, 364, n.1 (January 6, 2011), 43-50; and Gina Kolata, "Charles Byrne, the Irish Giant, Had Rare Gene Mutation," *New York Times*, January 5, 2011.

and researchers and legal scholars now resumed the call for the Hunterian at long last to comply with Byrne's deathbed wishes.⁸ An opinion poll on the issue published in 2011-2012 at the website *British Medical Journal* established that a majority of the 560 professional readers – a remarkable number of interested professionals – of the website responding to questions about the issue agreed.⁹ The time seemed especially ripe for the Hunterian to agree, because the museum was involved in physical renovation and a reorganization of its exhibits. But the Royal College of Surgeons nonetheless resolved in 2012 to continue to exhibit Byrne, though it is unclear what benefit can be derived from it beyond dazzling its patrons.¹⁰

While personally I believe that the Royal College of Surgeons is wrong on ethical grounds – refusing to honor the inviolability of a legitimate deathbed wish – in its decision to continue to display Byrne's remains, and that it would be best to make an explicit break with the trail of events that eventuated from John Hunter's scheming 234

⁸ Len Doyal and Thomas Muinzer, "Should the Skeleton of 'the Irish Giant' be buried at sea?" *British Journal of Medicine*, 343 (20 December 2011), 1290-1292, at www.bmj.com/content/343/bmj.d7597. A long thread of discussion by readers follows this posting in the journal's electronic "Rapid Response" format, and begins at the same location.

⁹ The poll and a summary of the most recent controversy over Byrne's skeletal remains is found in Thomas Muinzer, "A Grave Situation: An Examination of the Legal Issues Raised by the Life and Death of Charles Byrne, 'the Irish Giant'," *International Journal of Cultural Property*, 20, n.1 (April, 2013), 23-48.

Nearly 56% of those polled approved of burial at sea, 13% approved removal of the display but not burial at sea, and 31% approved of continuing the display of Byrne's skeleton.

¹⁰"Royal College of Surgeons Reject Call to Bury Skeleton of the Irish Giant," *The Guardian* (UK), December 22, 2011; Samuel J.M.M. Alberti, the Director of Museums and Archives of the Royal College of Surgeons of England, summarized the reasons for the decision of the Hunterian not to give up control of Byrne's skeleton and bury his remains according to his own wishes, citing the possibility that advancements in medical science may yet reveal further uses to which Byrne's bones may be put that we are not in a position to know at this time. To the argument advanced by proponents of substituting a manufactured skeleton of Byrne's dimensions for the true remains, Alberti argued that the public has the right and the desire to see authentic exhibits; see Alberti, "Should the Skeleton of 'the Irish Giant' be buried at sea?," February 10, 2012, at www.bmj.com/content/343/bmj.d7597/rapid-responses (accessed April 19, 2017).

years ago, that is not the point I wish to make in this brief essay. Instead, I would like to return to the debate about freaks and freak shows in our Disability Studies literature and pedagogy, and invite readers to interrogate the meanings of Charles Byrne's final testament. Whatever decisions Byrne made during his life about being displayed for money, he certainly made it clear that he preferred in death not to be displayed or have the natural decomposition of his body interfered with, but instead to be at the bottom of the English Channel, the destination his friends, who either lost or sold his corpse, were taking him to the night they were charged with its disposition.

In this context, Byrne appears to present us with a complexity of motivations worth considering. Whatever compromises he made with his dignity in order to make money, Byrne did not want to be a freak for eternity, and gawked at in perpetuity by crowds of spectators. His life had apparently been hard enough, as his pain and sickness and his probable self-medication through strong drink suggests. Thomas Muinzer, a legal ethicist at the University of Sterling in Scotland who has made extensive study of Byrne's life and death and has argued for compliance with Byrne's final wishes, maintains that, as his health declined with death near, Byrne knew that the body snatchers – *resurrectionists*, as they were then widely, ghoulishly if ironically, called – wanted to take control of his remains.¹¹

One can further root his last wishes in the Christian, village culture (whether Catholic or Protestant is not clear) in which he was raised, and provide some needed historicity to the examination of Byrne's resolve to escape from the clutches of those

¹¹As Schultz, *Body Snatching*, and Gordon, *The Infamous Burke and Hare* make clear the term "resurrectionists" was widely used in Anglo-American and British English in the nineteenth century to refer to *grave robbers*.

who would possess him after death. It has also been speculated that Byrne may well have feared that autopsy and exhibition might interfere with the final disposition of his soul – his hoped for true resurrection at divine rather than human hands – within the framework of his religion. In this, he was clearly choosing from a religious point of view the lesser of two evils. Protestant faiths and Catholicism do sanction burial at sea for those who die at sea, but the optimal disposition of a body in the Christian tradition is in hallowed ground that may be visited by loved ones for the purposes of offering prayers and communing with the spirit of the dead, and may also serve as a reminder of the eventual resurrection of all the faithful. Perhaps his suffering near the end preoccupied him from thinking too deeply about the matter. Or, perhaps the desire not to be interfered with in death caused him too much anxiety to inquire too closely when in the company of a minister or priest.¹²

Whether Byrne understood any of this from the standpoint of Christian tradition, we cannot know. What we can know is that this freak did not wish to be a freak forever, which sadly seems, at least to this point in time, to be his fate. And if not forever, than do we also have reason to believe he was ambivalent about being a freak in his own lifetime? But then what choice did he have?

¹²Cabbage speculates on possible religious motivations without being able to identify Byrne's own faith; Cabbage, "The Tragic Story of Charles Byrne, 'The Irish Giant'," p.6. On Catholic tradition, see, www.seaservices.com/catholic-burial-at-sea (accessed April 17, 2017). There have been a variety of understandings of Catholic doctrine on this subject and the nature of historical practices in any Catholic region is not always entirely clear. Protestant practices, outside the context of naval and merchant marine personnel who die at sea, are yet more obscure.