Mia Florin-Sefton //

In March 2008, The California Institute for Regenerative Medicine (CIRM) hosted a talk titled "A Spotlight on Deafness" [1]. The talk was one in a long series dedicated to discussing various conditions thought to be potentially treatable with the development of new embryonic stem cell therapies (ESC). It is noteworthy, however, that prior to this event, the patient advocates at the helm of California state politics had rarely had to seriously contend with, or consider, the perspectives of people with disabilities with regard to ESC research (Benjamin, 86). This despite the fact that questions surrounding ESC research, since their very conception, have famously always attracted a high pitch of fevered, furious public debate [2]. And yet, shortly after hosting "A Spotlight on Deafness," the unapologetic pro-cures agenda fronted by the CIRM—whose brash, impolitic slogan reads "Created by Californians. Curing the World"—became the subject of fierce attack. Indeed, as Ruha Benjamin records in People's Science: Bodies and Rights on the Stem Cell Frontier, patient advocates were finally made aware of rising discontent amongst disability activists—and, understandably, particularly amidst members of the Deaf community.

This fallout reached something of a perverse inaugural climax when Deaf activist "Mike X" [3] published on his popular blog the following headline: "Deaf Group Attacks Stem Cell Researcher for His Work on the Cure for Deafness" (Benjamin, 57). He proceeded to report:

Arrests were made against a small group of Deaf people who attacked a stem cell researcher for his work on finding a cure for hearing loss. The attack took place at the researcher's home where he sustained multiple injuries. He was treated at a nearby hospital and released. The attack occurred while he was home alone. Graffiti was spray painted on the living room walls and elsewhere in the victim's house with words like "Audism is wrong" and "Deaf babies do not need your help", along with several epithets. The group, based on the graffiti, name themselves ... "The Deaf Crusaders". [4]

As can likely be predicted, the comments section quickly became a fecund breeding ground of hot takes, troll baiting, and exaggerated conspiracy theories. Yet, as Benjamin describes it: "the ensuing conversation among Mike X and his readers did not express complete solidarity with the motivations or tactics of the Crusaders, neither did most of the participants align themselves with stem cell research and its pro-cures agenda" (58). However, in many ways, this bubbling controversy never lived past the point of fertilization, as three weeks following the original posting Mike X delivered another bombshell: the event had never taken place. Indeed, after explaining

that he had taken inspiration from the many debates that circle around deafness, amniocentesis and cochlear implants, he admitted that the attack and "the Deaf Crusaders" were simply a figment of his imagination.

This example of what some might understandably be tempted to dismiss as simply a case of "fake news" whips up a whole hurricane of ethical questions and controversies, not least the ethical perils of incentivizing or pre-empting violence through its intimation and imitation. Even so, Mike X's writings and actions do successfully diagnose many of the ableist paradigms that subtend what disability activist and scholar Eli Clare in his wonderful work *Brilliant Imperfection* has termed "the ideology of cure," as it subtends the pro-cures agenda more broadly [5]. Simultaneously, even if plagued by the fact of their falsehood, Mike X's actions spoke directly to many of the most contested questions concerning disability and deaf identity politics [6].

Thus, as many of his most engaged interpolators repeatedly attested, Mike X's fiction successfully captured real, breathing concerns regarding the direction, aims and presuppositions motivating much ESC research. Still, what remains uniquely arresting about this case is precisely the dilemmas surrounding and outcomes of its invention. To put it differently: why did Mike X risk making it up? And subsequently, why did his confession serve only to heighten the sense of inevitability and risk-laden suspense? As one commentator responded in the fallout of the final revelation: "but if not now, when?"

Thus, what is particularly arresting about this event, is the fact that the language of conjecture haunting Mike X's reporting speaks directly to what Jasbir Puar terms a "biopolitics of risk" (37). This she defines as a system that "situates disability within formulations or risk, calculation, prognosis, and statistical probability, whereby disability is understood not as phenomenological essence, identity or personal attribute, but as risk coding, as an embedded aspect of biopolitical population management" (36). To put it differently and in terms in keeping with this particular case, a biomedical complex that would recast "deafness" as a risk-laden deficit prime for intervention. Through the possibility of preemptive and preventive ESC therapies, patients are actively encouraged to act to avert or mitigate any risk of deafness. Crucially, one of the benefits of this heuristic is that it frames Mike X's actions as the direct result of the intense duress placed on subjects who must suddenly understand themselves to both be at risk and to be the calculus of risk.

More importantly, as Kaushik Sunder Rajan reminds us, "risk is" also "fundamentally implicated in a dialectical relationship between prophecy and contingency" (174). Here, Rajan uses the term "prophecy" to mean two things: firstly as a way of calculating contingency, through risk-benefit analyses that situates the possibility of a future illness amidst a whole set of calculations that view risk as capital. And secondly: as a means of taming that very contingency "at least partly by conjuring a tendential future through the prophecy" (175). As such, what is particularly striking with regard to the case of "The Deaf Crusaders" is the extent to which this practice of risk

strategizing—central to the epistemic and economic mechanisms through which populations have come under the jurisdiction of governing bodies—is directly mirrored by Mike X's fictitious ploy.

Indeed, by prophesizing an event that, as his commentators later hypothesized would become inevitable, Mike X attempted to catalyze a reaction that would work to tame that very contingency around its happening. For even as the reassertion of Deaf as a minority identity attempts militantly to resist the grammar of the hypothetical, through encouraging other members to discuss the event, Mike X was already actively encouraging others to engage in a "process of prophesying as a mode of coming to terms with risk" (Sunder Rajan, 175). As such it becomes possible to see how Mike X's risky prophecy actually mirrors, to some extent, the strategies of biopolitical risk management.

Of course, bitter irony lies in the fact that this system of hypothetical risk assessment and conjectural prophecy shares common ground with not only the logic of those investors who are encouraged to support and fund new biotech ventures but also the logic whereby by patients-inwaiting are encouraged to take preemptive or prophylactic action on the basis of diagnostic tests. This observation thus helps to brings my discussion to the last, slippery flipside of Mike X's throw of the dice. The fact is that his post on "The Deaf Crusaders," regardless of whether it provoked critique of the "pro-cures movement," nevertheless still participated in the sensationalist "hype" and "speculative vision" that continues to generate investments in the developments of such "cures" (Sunder Rajan, 106). Indeed, both Melinda Cooper and Sunder Rajan rigorously document how the biotech industry survives only through generating perpetual, sensationalist hype and conjecture—all processes that contribute to the constant sense of collective apprehension and anticipation: "if not now, when?"

On this question, it is worth stressing that no "miracle" cure for deafness has yet been discovered, an assessment that comes almost exactly ten years after the lecture of a "Spotlight on Deafness" that was to prove so controversial. For as Nikolas Rose reminds us, regardless of its hyperbolic advertising and celebrated talk series, "biomedical innovation rarely triggers epochal transformation" (88). Indeed miracle cures are rarely found, always marketed, and relentlessly hyped. This is all to compound the heavy irony that, even as Mike X and other participants might engage in protesting some of the work in stem cell research, their very act of prophesying about it also participates in the promissory hype. A reflection that inevitably prompts the bitter rejoinder: for whom do risks of this kind pay off?

[1]Information on, and a link to a video of, the talk can be found here: https://www.cirm.ca.gov/our-progress/video/spotlight-deafness-seminar-ebenezer-yamoah-phd

[2] For a comprehensive summary of these debates see: Ruse, Michael, and Christopher A. Pynes. "The stem cell controversy: Debating the issues." (2003); Holland, Suzanne, Karen Lebacqz, and Laurie Zoloth, eds. *The human embryonic stem cell debate: Science, ethics, and public policy*. Vol. 3. MIT Press, 2001; Ruha Benjamin's *People's science: Bodies and rights on the stem cell frontier*. Stanford

University Press, 2013; and Charis Thompson's *Good science: The ethical choreography of stem cell research*. MIT Press, 2013.

[3] Here I use square quotes to draw attention to the fact that "Mike X" is a pseudonym. However from this point on, predominantly for the sake of ease, I will refer to the author of the blog simply as Mike X, and with male pronouns.

[4] The blog, posting and comments can be found at Kokonut Pundit, available at http://kokonutpundits.blogspot.com/2010/02/deaf-group-attacks-stem-cell-researcher.html. While the blog used to be open to the public, since the controversy only previously approved members are permitted access.

[5] Here I use the phrase "pro-cures agenda" in the sense outlined by Ruha Benjamin in *People's Science*; to name a consensus among patient advocates that certain cognitive or physical differences should be classified as disorders, whilst organizing around the right to defend the quest for biomedical cures to these disorders. By the term "ideology of cure" Eli Clare is referring to the common presumption that all "body-minds" can be improved, and are therefore always in need of fixing. It is this attitude that I address in this paper, as the direct outcome what I am calling a "biopolitics of risk".

[6] For a thorough overview of the central debates see: Scott-Hill, Mairian. "Deafness/Disability—problematising notions of identity, culture and structure." *Disability, culture and identity*. Routledge, 2014. 102-118.

Works Cited:

Benjamin, Ruha. *People's Science: Bodies and Rights on the Stem Cell Frontier*. Stanford University Press, 2013.

Clare, Eli. Brilliant Imperfection: Grappling with Cure. Duke University Press, 2017.

Cooper, Melinda E. *Life as Surplus: Biotechnology and capitalism in the neoliberal era*. University of Washington Press, 2011.

Puar, Jasbir K. The Right to Maim: Debility, Capacity, Disability. Duke University Press, 2017.

Rajan, Kaushik Sunder. Biocapital: The Constitution of Postgenomic Life. Duke University Press, 2006.

Rose, Nikolas. The Politics of Life Itself: Biomedicine, power, and subjectivity in the twenty-first century. Princeton University Press, 2009.

Sparrow, Robert. "Defending deaf culture: The case of cochlear implants." *Journal of Political Philosophy* 13.2 (2005): 135-152.