Conclusion

This book began with a twofold challenge. The first was to go beyond the critical perspective that Alice Rivières vehemently established as she apprehended the violence inherent in diagnosis as more than the failure of a particular doctor or institution. Our task, instead, was to make sense of it as the effect of a given epistemological and deontological regime. The second challenge was to resist the widespread notion that new techniques come into being with already stabilized, clearly defined problems, and that our mandate was to react by taking ethical and legal measures like setting protocols, establishing terms of accessibility, and other guidelines.

To depart from this approach, I suggested we take up an ecological perspective that would force us to elaborate well-constructed problems in relation to the new technical entities that inhabit our world. These problems would allow us to establish more constructive relationships with these entities. On this basis, rather than knowing whether a technique is in itself admissible or not, the question becomes one of knowing how we might assemble ecological milieus or situations fostering the existence of the conditions needed to most assuredly and effectively welcome an entity like the creature commonly known as the “predictive test.”
Yet modern medicine – in the name of the scientific recognition to which it aspired – separated the sick person from the disease and thus interrupted the doctor–patient relationship. At the same time, it drew upon a radical epistemological separation of facts from values in order to delegitimize any modes of access to disease deemed “unscientific” by modern standards. There is little room for the patients’ perspective within this kind of medicine. What such perspectives might contribute to diagnosis as well as to therapeutic decisions must, in keeping with this logic, remain at a minimum. Only in this way could medicine achieve and sustain its aspiration to scientific rationality, which is to say, to the systematic universalization of medical knowledge. Within a system like this, the patient or anyone else lacking medical qualifications, no matter how profound their connection to the illness, is denied from working towards fashioning a given disease on the basis of experience or artistic, historical, or philosophical know-how. For as we have seen, to put it in the plainest terms, the very people touched by disease are, strictly speaking, no longer the objects of medicine. This is especially due to the increasingly dominant role ascribed to quantitative methods within health. Coinciding with the emergence of the 19th-century social hygiene movement, the close connection between medicine and statistical knowledge gradually imposed itself upon all its domains. So-called “evidence-based medicine” has continued this tradition, and since the 1990s, statistically derived (and therefore unimpeachable) knowledge has been elevated to the rank of the central truth criterion.

Taken to its limit, it can be said that from a statistical point of view the patient is not a person. They are not somebody but rather, following Tobie Nathan, anybody
The regime of modern medicine is intimately entwined with this practice of anybodification. When the doctor foretells that the “verdict” Alice receives of “44 CAG repetitions” will be “unbearable,” this speech act can be understood as the effect of the statistical transformation of a person into an anybody. It is a form of proof-making that surreptitiously shifts from constative utterance (“44”) to performative utterance (“unbearable”). The two kinds of utterance merge through this operation, dissembling a fundamental point: the term “unbearable” refers to a statistical monstrosity whereby anybody presenting forty-four repetitions will have an unbearable future. And yet such a statement fails to account for Alice’s actual and concrete future.

Stephen J. Gould offers perhaps the most compelling account of the traps and devastating effects to which statistics give rise in relation to life-changing diagnoses. In a short piece eloquently titled “The Median Isn’t the Message,” Gould writes that in 1982 he learned he “was suffering from abdominal mesothelioma, a rare and serious cancer.” He then decided to review the latest literature on this form of cancer. “The literature couldn’t have been more brutally clear: mesothelioma is incurable, with a median mortality of only eight months after discovery.” Then, Gould explains, he used his understanding of the purposes and limits of statistics, learned from evolutionary biology, to convince himself that this scientifically founded information did not mean, as one generally presumes, that he would invariably cease liv-

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3 Ibid.
ing in eight months’ time. His main argument is that our Platonic heritage, with its emphasis on clear distinctions and firm boundaries, beguiles us into radically misinterpreting statistical studies – “opposite to the appropriate interpretation in our actual world of variation, shadings, and continua.”

Instead of considering variations as the “hard realities” and means and medians as abstractions, our customary view of things has us take up the polar opposite position. We are used to conceiving of “means and medians as the hard ‘realities,’ and the variation that permits their calculation as a set of transient and imperfect measurements of this hidden essence.” Therein lies our fundamental mistake, a mistake that comes with an existential threat. In effect, when “the median is the reality and variation around the median just a device for its calculation, the ‘I will probably be dead in eight months’ may pass as a reasonable interpretation.” Statistics, it is plain to see, are a total abstraction translated into numbers. It is therefore from the perspective of science itself that the narrative hold they have over the individual must be called into question. We must do away with the habit of automatically turning means and medians into proof, deemed valid for a given concrete case such that its distinctiveness is not taken into account, not even gesturally or provisionally. In effect, if we emphasize variations, the only person whose life expectancy is reduced to eight months is an anybody, an anybody who only exists in the statistical realm.

In this sense, the task of elaborating a milieu that is capable of welcoming our creature, the “predictive test” for HD, is above all one of resisting the hold of the anybody. From within this context, resisting this hold assumes the ability to become able to recognize that test

4 Ibid., 28.
5 Ibid.
6 Ibid.
results which appear to take an abstract form, such as the number “44,” are not explanatory but instead, because they address a concrete person, are first and foremost a riddle. What is to be done, then, is to take care of this riddle together and, along the way, take lesson from the proliferating becomings contained within.