Afterword

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Afterword

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I am writing this afterword as almost ten years have passed since the founding of Dingdingdong, the Institute for the Coproduction of Knowledge about Huntington’s Disease. Initiated by Emilie Hermant and Valérie Pihet, both Katrin Solhdju and myself are among its members. This collective began its adventure following Alice Rivières’s early encounters with a medical establishment that proved to be in complete disarray in the face of Huntington’s disease, its definitions, its incurability, its heredity, and its predictive testing. In 2013, Alice Rivières recounted this experience in *The Dingdingdong Manifesto*, the inaugural publication of the Éditions Dingdingdong publishing house. Two years later, Éditions Dingdingdong published the French edition of *Testing Knowledge*. These two texts make up the present volume.

Founding the Dingdingdong Collective turned out to be a transformative experience for all of its members, whatever their practice. This is because Dingdingdong creates an understanding of these same practices such that they warrant the interest of the virtual community concerned with, attached to, or connected through the questions Huntington’s disease raises. Joining Dingdingdong therefore involves actively and creatively situating ourselves as a part of this community, as subjects touched by these questions.
Katrin Solhdju’s *Testing Knowledge* is the work of a historian and epistemologist of medicine and its experimental practices. However – and this is no contradiction – it is also a book committed to, thought through, and written “in the presence” of people who have decided to take the genetic test that stands to identify them as carriers or non-carriers of the genetic mutation responsible for Huntington’s disease. It puts into question a diagnosis, one whose predictive power is matched only by the disarray it causes; because, in this instance, for every call of “now that we can know,” there is never a corresponding “here’s what we can do.” In medicine, the idea that once a “cause” is identified then treatment follows is alive and well. Research is ongoing. Its temporal horizon, however, is too far off to enable those who pronounce the diagnosis to follow it with words of hope and encouragement (or the prospect of good news to come).

When reduced to a “fact” – you’re either a carrier or you aren’t – diagnosis can crush the very person who wanted to know. As she explains in *The Dingdingdong Manifesto*, Alice Rivières experienced the announcement of her test results as an extremely violent verdict. The doctor knows what will happen to her, and this knowledge brooks no appeal. She cannot do anything but await the inevitable, the onset of the first symptoms that mark the beginning of a slow decline. Solhdju reminds us that we use the word “prophet” to refer to someone who speaks in the name of a power that legitimates or authorizes their discourse. The doctor prophesizes in the name of the power of scientific truth, but it is a truth that deprives Alice of any possible hold on her own life, because medicine has no hold over the disease. Dindingdong was created, as a collective, on the basis of Alice’s refusal to let this knowledge crush her. It is not a matter of denying its truth, but rather, of repopulating the world that it depleted.

Solhdju argues for an ecology of diagnosis, that is to say, for an approach that does not separate diagnosis
from the milieu that confers meaning upon it and lends it consequence. It is worth emphasizing that such an approach is not *critical* in the sense of aiming to reduce diagnosis to a mere function of its milieu. Coming from someone who treats people, a diagnosis is *agentive*, it is a vector of transformation in and of itself, and as such has a stake in the art of healing. Hence, the milieu does not explain diagnosis. Rather, it achieves its explanation *through* diagnosis. For Solhdju, the ecological approach “problematizes” because it excludes any position of exteriority or detachment. It seeks to “posit” a problem “well.” This does not mean making the problem go away, but rather, deploying it in a mode through which it acquires irreducible bearing and significance.

You might say that Solhdju offers her own response to the call Bruno Latour made in his landmark article “Why Has Critique Run Out of Steam?” After glossing the ways in which the “merchants of doubt” captured and repurposed the critical approach, he asks: “Can we devise another powerful descriptive tool that deals this time with matters of concern and whose import then will no longer be to debunk but to protect and care, as Donna Haraway would put it? Is it really possible to transform the critical urge in the ethos of someone who *adds* reality to matters of fact and not *subtracts* reality?”

This is no coincidence but the trace of a common commitment: whether it is the “fact” that climate scientists’ observations and models allow for a conclusion about manmade climate disruption or the “fact” that particular genetic traits allow for the predictive diagnosis of Huntington’s, each requires commitment as a “matter of concern” but this does not mean simply yielding or deferring to them. They must take on a greater reality than the ab-

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testing knowledge

stract reality of “Q.E.D.” For facts like these say nothing about the consequences of their demonstration. Indeed, it is in this sense that they differ from the “experimental fact.” Solhdju reminds us that the experimental fact’s success hinges on the possibility of the experimenter withdrawing, avowing that the experimental set-up allows the phenomenon under investigation to “speak for itself.” However, the people it addresses, other experimenters, do not suffer a verdict. Rather, they are concerned: they go on to explore the consequences of their colleagues’ success, which is to say they augment its reality.

Solhdju’s ecological approach draws a strong distinction between the respective milieus of the “experimental fact” and the “clinical fact,” even though so-called “evidence-based” medicine insists on their common ancestry. Facts are “agentive” in both instances; they prompt action, although not in the same way. However, this claim to common ancestry is itself agentive. This is because the doctor does not take on the role of mediator, of someone who creates a putatively therapeutic relationship between the patient and “the facts” by “adding” something to “the facts” such that they become the centerpiece of a healing process. Instead, the doctor plays the role of mere intermediary, that is to say, of the spokesperson for a verdict wrought from another order of knowledge altogether, so-called objective knowledge, which characterizes what “objectively” ails the patient.2 Of course, the doctor can profess their confidence in a given course of treatment, the effectiveness of which is also grounded in “facts,” and it is assumed that they always behave “humanely.” However, they can go no further. Another agen-

2 A central distinction Bruno Latour has introduced is the difference between an intermediary, an entity that loyally translates relations but does not transform them, and a mediator, an entity that has the capacity to create relations and transform them. See Bruno Latour, *Reassembling the Social: An Introduction to Actor-Network Theory* (Oxford: Oxford University Press, 2005), 39.
tive figure haunts the stage: the charlatan. Their art runs the risk of producing therapeutic effects reminiscent of medicine’s shameful past.

Within this milieu – which requires that the doctor, lest they pass for a charlatan, be a loyal intermediary and refrain from adding anything to the facts that might commit them to a healing relationship – the predictive diagnosis for Huntington’s disease is a disturbance that gives rise to what Solhdju terms an “ecological crisis.” It is as if the novel entity’s very presence is disordering and, barring a disastrous turn of events, calls for the problematization of roles and positions. In following Nancy Wexler and referring to this entity as “the creature,” she irresistibly turns our thoughts toward Frankenstein’s creature, that unfortunate being hated by its creator and whom this hatred, the father’s refusal to invent a way of welcoming it, turned evil.

How can the Hippocratic oath’s call to “do no harm,” the doctor’s primary duty, combine with the effective malevolence that this loyal intermediary must present as factual information? The doctor may claim that doing no harm in this instance means respecting the autonomous subject who must confront the naked truth, i.e., find the inner resources needed to mourn any hope of leading a normal life. However, with a curious sleight of hand, the intermediary then transforms themself into conscience’s guide. They direct the patient to give up on the fantasy of consolation “for their own good.” This is, to be sure, an ecological crisis: a fact becomes a duty.

The Dingdingdong collective does not take blame as its vocation. However, it wagers that narratives other than decline without remedy and experiences other than irretrievable displacement and fractured relationships exist and can, when activated, become agentive, repopulating the imaginations of people concerned with Huntington’s disease. They may be carriers, sick persons, loved ones, or medical and paramedical caregivers; we name them
“users,” because the task is to cultivate “usages,” ways of doing and building relations. This is Solldju’s wager. Nothing will make the telling of a “positive” genetic test result something other than an ordeal (épreuve) – a testing experience for the person who thereafter knows they are a carrier, for their loved ones, and also for the doctor who has to make the announcement. The “creature,” however, remains silent about the nature of this ordeal. What speaks in their name is, above all, the doctor’s knowledge of medicine’s powerlessness.

In a video produced by Dingdingdong in 2013, this doctor’s name is Marboeuf, and he recounts his confrontation with Alice Rivières’s sister who reproaches him for not having said that he did not know. Yes, she allows, there may be statistics, but they are just as silent about what will happen to her sister in particular. Giving voice, as Solldju observes, to those to whom the ordeal is presented as something to which they will be subjected, when it is in fact the doctor who is subjected to medicine’s powerlessness to act, Rivières’ sister adds: “The truth of our disease does not belong to you or, at any rate, at least not only to you.” This presents an opportunity to propose a speculative narrative. What if, instead of buttressing his clear conscience as “someone who is no charlatan, who sticks to the facts,” Doctor Marboeuf took an interest in the way that elsewhere (e.g., in the Netherlands) the “truth of medicine” exists only in caregiving, in spatial arrangements, in inventing techniques for enabling life, modes of attention, as a range of ways of doing everything possible to “dedramatize” this sickness? Hence, another ecology of illness would be possible, an ecology that would multiply agentive systems, not to produce miracles but rather to give living well a chance.

These days, a whole range of user groups are taking shape, some with doctors and some without, creating new milieus, to forge new ecologies for the sicknesses that ail them or to “depathologize” the singular disorder with
which they live. Hence, voice hearers refuse to accept that their voices belong to schizophrenia as a psychopathological category. As for Dingdingdong, we reject the term “neurodegenerative” as applied to Huntington’s disease, we can accept the term “neuroevolutive,” yet refuse to isolate the neurological from the relationships that come together or fall apart within its multiple milieus. Can we really imagine a doctor turning an unfavorable test result into the revelation of a metamorphic future and the need to “prepare the soul” so that this metamorphosis goes “as well as it can, despite the intense turbulence it will not fail to bring about”?3

Can we also imagine that a doctor, reading the final pages of Solhdju’s book, would seriously consider the connection she ventures to draw with the oracular practices of the Pythia at Delphi? For the Pythia was also an intermediary, yet she belonged to a world in which people knew that contact between her and her god ran the risk of destructive possession and that ritual precautions were necessary for her own safety. It was also known that naked prophetic speech was dangerous, requiring that mediators intercede and interpret it. Today, the oracles are gone but seers do still exist. One such person, Maud Kristen, agreed to extend the speculative story of Doctor Marboeuf by addressing a letter to him. The following is an excerpt:

Your practices, like mine, question the future and interpret data using various markers.

You question and interpret samples, as do I... Your media are blood or secretions. Mine are initials, images, cards, or photographs. Divination or medical ex-

aminations deliver verdicts. But haven’t you forgotten that only your patient or my client turns this verdict into a “destiny”? Haven’t you forgotten that they are in no way reducible to the bad news afflicting them?

You and I, Doctor, we both own a diagnosis. That’s all. That’s quite a lot already. But we never own what they will weave from their “bad news,” never what their life will become after the announcement, nor the sense they will or won’t make of all this.

No point, therefore, trying to convince them that everything is done for. The only thing that’s done for is perhaps or probably, I concede, life as an able person for much longer, but it’s not the man or woman you have before you and about whom you know nothing.4

For Katrin Solhdju, the historian and epistemologist, the question of predictive diagnosis for Huntington’s disease forced her to vacate her analytical position, not to abandon its rigor but rather its presumed detachment. She had to give this question the form of a riddle that compels thinking and imagining. What this meant, she notes, was going “one step further to interrogate the propositional potential of [her own] conceptual, historical, and empirical research.” In order to “posit the problem well,” to give it a reality that might be shared with those concerned with this problem, she dared to take seriously the question that the presymptomatic test for Huntington’s disease raises. This is not one of prediction in general but the question of people who “tell the future,” who tell a person’s future when asked. The fact that Solhdju queries what makes someone capable of this – whether that is

genetics, cards, photographs, or the Pythia’s god Apollo – is not a sign of disrespect or irreverence, it shows no desire to scandalize those for whom only medical prediction is objective. The question is not what authorizes such knowledge but the ordeal (épreuve) it enacts. What is specific about the situation of the doctor announcing test results is, perhaps, that the ecology of the medical milieu is unfavorable to the culture of protection that the “foreteller’s’” position requires and to the multiplication of mediators necessary to add reality to the genetic “fact.”

In Alice Rivières’s case, the medical team’s preoccupation turned on the following question: can the person who asks to know withstand the telling of a future that will one day be theirs? This is a bad question, as the genetic fact is not “their” future. However, it is a question that articulates the intermediary’s drama: what they have to foretell may lead to suicide, but the intermediary can only impart this knowledge in all its horror.

Of course, Solhdju’s ecological approach does not call for doctors to become possessed by a divine force or to learn how to read cards. But it does call for the coproduction of all kinds of knowledge and practice that make up the landscape awaiting the carrier. It calls for doctors to not leave the recipient of “bad news” alone before the desert of a life deprived of possibility, to add to this news some gesture of interest in a landscape of possible relations, encounters, futures, and histories. Such is the landscape that will give truth to diagnosis, the truth of a life that can be lived well all the same.