

Between truth and hope: on Parkinson's disease, neurotransplantation and the production of the 'self'

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ABSTRACT

In this article, we argue that contemporary biomedicine is shaped by two, seemingly incommensurable, organizational logics, the 'regime of truth' and the 'regime of hope'. We articulate their features by drawing on debates sparked by the recent clinical trial of a new approach to the treatment of Parkinson's Disease. We also argue that the 'self' is configured in the very same process whereby these two organizational logics interlock and become mutually dependent, so that the 'self' might be said to be the *effect* of a 'parasitic' relationship between the regimes of 'truth' and 'hope'. We then bring these two arguments to bear on the contrasting views of the relationship between embodiment and political subjectivity articulated by Michel Foucault and Giorgio Agamben, on the one hand, and Paul Rabinow and Nikolas Rose, on the other hand.

Key words biopolitics, neurosciences, self, stem cells, subjectivity

WHO IS ALFRED?

We would like to open a series of critical reflections on the contemporary, biomedical production of the 'self' with the following excerpt from Jonathan Franzen's novel *The Corrections*:

Alfred was standing in the master bedroom wondering why the drawers of his dresser were open, who had opened them, whether he had opened them himself. He couldn't help blaming Enid for his confusion. For witnessing it into existence. For existing, herself, as a person who could have opened these drawers.

'Al? What are you doing?'

He turned to the doorway where she'd appeared. He began a sentence: 'I am . . .' but when he was taken by surprise, every sentence became an adventure in the woods; as soon as he could no longer see the light of the clearing from which he'd entered, he would realize that the crumbs he'd dropped for bearings had been eaten by birds, silent deft darting things which he couldn't quite see in the darkness but which were so numerous and swarming in their hunger that it seemed as if they were the darkness, as if the darkness weren't uniform, weren't an absence of light but a teeming and corpuscular thing, and indeed when as a studious teenager he'd encountered the word 'crepuscular' in McKay's *Treasury of English Verse*, the corpuscles of biology had bled into his understanding of the word, so that for his entire adult life he'd seen in twilight a corpuscularity, as of the graininess of the high-speed film necessary for photography under conditions of low ambient light, as of a kind of sinister decay; and hence the panic of a man betrayed deep in the woods whose darkness was the darkness of starlings blotting out the sunset or black ants storming a dead opossum, a darkness that didn't just exist but actively consumed the bearings that he'd sensibly established for himself, lest he be lost; but in the instant of realizing he was lost, time became marvellously slow and he discovered hitherto unguessed eternities in the space between one word and the next, or rather he became trapped in that space between words and could only stand and watch as time sped on without him, the thoughtless boyish part of him crashing on out of sight blindly through the woods while he, trapped, the grownup Al, watched in oddly impersonal suspense to see if the panic-stricken little boy might, despite no longer knowing where he was or at what point he'd entered the woods of this sentence, still manage to blunder into the clearing where Enid was waiting for him, unaware of any woods – 'packing my suitcase,' he heard himself say. This sounded right. Verb, possessive, noun. Here was a suitcase in front of him, an important confirmation. He'd betrayed nothing.

But Enid had spoken again. The audiologist had said that he was mildly impaired. He frowned at her, not following.

'It's Thursday,' she said, louder. 'We're not leaving until Saturday.'
'Saturday!' he echoed.

She berated him then, and for a while the crepuscular birds retreated, but outside the wind had blown the sun out, and it was getting very cold. (Franzen, 2001: 12–13)

Alfred and Enid Lambert have three children and *The Corrections* recounts the struggles of this fictional family with Alfred's progressive slip toward dementia and death. Alfred is confronted with the terminal effects of Parkinson's Disease (PD); Enid is Alfred's stubborn and ever hopeful wife; Gary is the pragmatic, eldest son, who is told by his own wife to seek professional advice for his 'depression', if he wishes to keep his marriage intact; Chip is the youngest son who was fired from his post of professor in cultural theory, for sexual harassment; and Denise is the emotionally confused daughter and chef. Alfred's rapidly deteriorating condition is the point of contention that brings this seemingly dysfunctional family together. According to Gary and Enid, Alfred should be convinced that, at the very least, the Axon Corporation, which has exploited Alfred's invention of a semi-conducting material to develop a new treatment for PD, owes him inclusion in its experimental trials of this new treatment. Denise, however, fears that she will be forced to house her parents, if Alfred is to be able to participate in the trials. Finally, Chip believes that Alfred should be left alone, to deal with his mortality in his own way. As these four negotiate between themselves, Alfred, the once youthful reader of Arthur Schopenhauer, who, like the German philosopher, has always believed in the meaninglessness of the world, becomes progressively detached from all these positions. For the reader, as for the four other members of the Lambert family, Alfred's disengagement is both frustrating and puzzling: why is Alfred not interested in getting better? Why will he not at least admit to the hopelessness of his situation?

In this article, we try to articulate a possible answer to the puzzle that Alfred poses. Recognizing that, in *The Corrections*, PD figures both as a substantive topic and a metaphorical device, our thesis is that the increasingly familiar predicament in which all five members of the Lambert family find themselves captures a wider tension structuring knowledge and experience of the 'self' within the domain of contemporary biomedicine. We argue first that biomedicine is shaped by two conflicting organizational logics, which, in many ways, evoke the divisions within the Lambert family. These two organizational logics are the 'regime of truth' and the 'regime of hope'. While undoubtedly courting confusion with the medical 'regimen', we none the less wish to label these organizational logics as 'regimes' to thus emphasize not

just the public articulation of particular political subjectivities, usually associated with the word 'discourse', but also their embedding in usually far less visible social networks and material practices (see Foucault, 1991; Thévenot, 2001). We will attend to these two organizational logics by drawing on the debates recently sparked by the clinical trial of a new approach to the treatment of PD, examining in considerable detail conflicting opinions about the viability, desirability and outcome of the trial. Importantly, we do not wish to imply that the organizational logics and conflicts to which we attend are in any way novel to the domain of biomedicine (see, for example, Marks, 1992; 2000). We do wish to note, however, that clinical trials no longer are a vehicle for an impossible escape from politics, but have instead become the medium of political engagement within the biomedical domain (Epstein, 1996; see also Dehue, 2002). Having established this opposition, we argue secondly that a particular configuration of the 'self' is constituted in the very same historical process whereby the two, largely autonomous, organizational logics eventually interlock and become mutually dependent. In other words, we address the way in which a particular configuration of the 'self' might be said to be the historical *effect* of an increasingly 'parasitic' relationship between the regimes of 'truth' and 'hope' (see Serres, 1982; Brown, S., 2002). We will conclude by drawing on this particular understanding of the relationship between 'truth', 'hope' and the 'self' to answer the questions that Alfred's disengagement poses for both his fictional family and that reader of *The Corrections* who is mindful of all their contemporary resonance.

PUTTING NEUROTRANSPLANTATION TO THE TEST

On 3 March 2001, few readers of the *Guardian*, a leading British daily newspaper, could have failed to take note of the headline and picture shown in Figure 1 (see also Dumit, 2004).

Two days later Sophie Petit-Zeman, one of the *Guardian's* writers, fleshed out the dramatic headline by writing that:

Earlier this week it was announced that a trial of a new treatment for Parkinson's disease had, for some patients, gone horribly wrong. A group of volunteers in the US had foetal cells transplanted directly into their brains, in the hope that they would survive and produce dopamine, the 'chemical messenger' missing in patients suffering from Parkinson's. But the researchers were horrified to discover that instead of being helped by the experiment, a small number of the patients got much worse. *The cells appear to have gone into overdrive, producing too much dopamine and causing the patients to writhe and jerk their heads*

Parkinson's miracle cure turns into a catastrophe

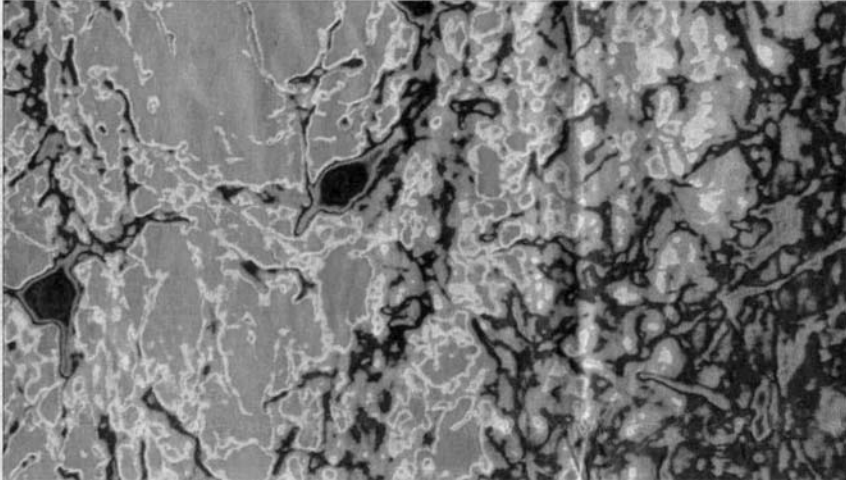


Figure 1 *Guardian*, 3 March 2001.

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uncontrollably. Unlike many experimental procedures, scientists have no way of reversing this particular treatment. The experiment has been stopped completely, prompting despair in many sufferers who hoped it offered a possibility for a cure. (Petit-Zeman, 2001; emphasis added)

While, for most readers, this would have been their first encounter with the field of neurotransplantation and the therapeutic, intracerebral implantation of embryonic neuronal material, for those involved with PD, either through their research, their investment, their care of others or their personal experience, this was very important news. The Parkinson's Disease Society, the leading British charity in the field, for example, was quick to position itself by announcing that 'despite setbacks in recent surgical trials', the intracerebral implantation of embryonic neuronal tissue provides 'early evidence and real hope of a breakthrough' in the treatment of PD (Parkinson's Disease Society, 2004). Martin Edwards, the chief executive of ReNeuron PLC, a company specializing in the development of biological products for the treatment of neurological disorders, was of the same opinion. Even Sir Iain Chalmers, 'director of . . . an international organization that collects evidence

on experimental treatments, and a leading expert on clinical trials', is reported to have acknowledged the ethical problems raised by human experimentation, but to have none the less maintained 'that he would have participated in the trial himself. In the sense that any results, even negative ones, are invaluable, he persists in viewing this experiment as "a tremendous success"' (Petit-Zeman, 2001). Such 'negative' results, however, did not constitute a positive outcome for all parties involved. Thus, another report on the trial, this time in the *New York Times*, suggested that professional opinion was far more divided than the *Guardian's* opposition of public and professional responses would suggest. In this report, some researchers appeared to call for the halting of all transplants of embryonic neuronal tissue and the focusing of research on more reliable sources of implants, such as stem cells, the undifferentiated, pluripotent cells that constitute the early embryo. Others appeared instead to question the legitimacy of the entire enterprise, because, either way, it involved the exploitation of human embryonic material (see Kolata, 2001). While it is tempting to attribute this more strictly professional disagreement to a peculiarly American debate over the legal framework for research on stem cells and associated technologies, such an interpretation oversimplifies the positions taken, because a number of other actors, removed from this peculiarly American context, also felt that the outcome of the trial called the future of stem cell technology into question. We suggest that, to understand the linking of the trial and the future of stem cell technology, we must first understand the conditions under which the trial was conceived and conducted.

While the use of L-DOPA (L-3,4-dihydroxyphenylalanine) as a pharmaceutical treatment for PD gained increasing support from the mid-1960s onward and has today become a stable component of the therapeutic repertoire, the understanding of underlying mechanisms still is a matter of debate (Hornykiewicz, 2002). Moreover, it is widely agreed that the use of L-DOPA does not in fact provide a satisfactory treatment of PD. As much as L-DOPA might increase the neuronal synthesis of dopamine in those parts of a particular region of the brain, the *substantia nigra*, that have not yet degenerated, it neither slows down nor arrests the more general process of neuronal decay.

Over the same 40 years, some researchers have argued that the transplantation of neuronal tissue and consequent modification of neurophysiological function in laboratory animals suggests that implanted neurons can bypass degenerating ones and re-establish physiological transmission between the *substantia nigra* and the *striatum* regions of the brain (see Figure 2). As such, they have also argued that neurotransplantation might offer a more effective approach to the treatment of PD than the use of L-DOPA (see Breeze and Wang, 1999). Since the late 1980s, there have therefore been numerous 'open' clinical trials of the intracerebral transplantation of embryonic neuronal

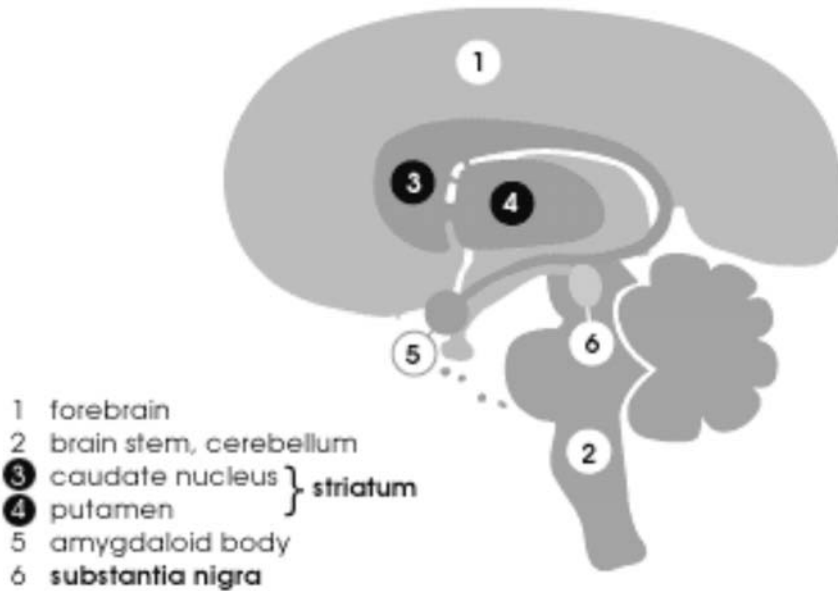


Figure 2 The brain.

Credit: Siamhealth.net

tissue. These were trials involving the statistical comparison of pre- and post-operative clinical condition of patients who had volunteered to have embryonic neuronal tissue implanted in their brain. Although most of these trials suggested that neurotransplantation offered a viable approach to the treatment of PD, it remained controversial, largely for the following two reasons. The first was that there were strong objections to its dependence on implants collected from aborted fetuses, not only due to moral objections to abortion, but also due to concern about the possible abusive exploitation of the human body (see Boer, 1999). The second reason was that, from the perspective of health care buyers and providers, in the context of an increasingly managerial approach to health care, neurotransplantation was not only a dangerous procedure, but also one that was expensive and difficult to standardize (Blue Cross/Blue Shield, 2001).

In 1994, as a consequence of the above concerns, the United States National Institutes of Health (NIH) took an initiative that is characteristic of post-war health care politics (Marks, 1997; Timmermans and Berg, 2003). The NIH attempted to settle the debate over the value of neurotransplantation for PD by sponsoring a trial that could be seen as methodologically sound by both the supporters and opponents of the procedure. More specifically, it decided to sponsor a 'double-blind, placebo controlled' trial of the intracerebral implantation of embryonic neuronal cells in 40 patients that

were afflicted by PD. As Curt Freed, the neurosurgeon at the University of Colorado who was charged with the responsibility of conducting the trial, recalls in the final report on the trial, 'transplantation of embryonic dopamine neurons into the brain of patients with Parkinson's Disease has proved beneficial in open clinical trials . . . [but] . . . whether this intervention would be more effective than sham surgery in a controlled trial . . . [was] . . . not known' (Freed *et al.*, 2001: 710). The patients were therefore divided into two groups, one in which cultured cerebral tissue from four human embryos was implanted bilaterally, along 30- to 40-mm needle tracts in the *putamen* region of the brain, and one which underwent 'sham surgery', in this case, the boring of cranial holes without any placement of the embryonic cells. The primary evaluation did not show any significant differences between the treatment and control groups: the recipients of the implants showed better outcomes in the 'objective measurements of PD', but some of the recipients eventually developed dyskinesias, that is, abnormal and uncontrolled movements, typically 1 year after surgery (National Institute of Neurological Disorders and Stroke, 2000). As noted by Sophie Petit-Zeman, these dyskinesias were attributed to the uncontrolled growth of the implanted neuronal tissue. This said, by 2000, the Blue Cross/Blue Shield Technology Evaluation Center was anxious to advise health care buyers on the relative merits of pharmacological and surgical approaches to PD, presumably because the latter was increasingly being offered to those affected by PD and Blue Cross/Blue Shield was being asked to cover its considerable cost, US\$40,000 (see Kolata, 2001). While the Blue Cross/Blue Shield Technology Evaluation Center expressed therefore some interest in the impending, final report on the trial, it undertook its own statistical review of earlier 'open' clinical trials and concluded that the surgical approach did not in fact provide a viable alternative to pharmacological treatment (Blue Cross/Blue Shield, 2001; see also Polgar *et al.*, 2003). In other words, it seemed to the Blue Cross/Blue Shield Technology Evaluation Center that the NIH trial could not add very much to the picture generated by its statistical review, and, when the final results of the trial were eventually released, what it added was not the greater clarity to which the NIH had aspired, but still more doubt about the effectiveness of the surgical approach to PD.

Importantly, the NIH trial was not problematic simply because its results did not in fact settle the questions about the effectiveness of the surgical approach to PD, but because the methodological design of clinical trials was also called into question. As Roger Albin, a neurologist at the University of Michigan, noted, 'the recent use of sham surgery in trials evaluating efficacy of intracerebral fetal tissue graft in Parkinson's Disease has highlighted the ethical concerns associated with sham surgery . . . [but] appropriate clinical trial design, sometimes including sham surgery, is needed to ensure that false positive trial results do not occur and endanger public safety' (Albin, 2002:

322). Albin was seeking thus to respond to those observers who, after the release of the trial's results, raised questions about the ethics of 'human experimentation', and, at the very least, called for both the abandonment of randomized controlled trials and a return to comparisons of pre- and post-operative conditions (see Dekkers and Boer, 2001). Such questioning, however, was not the exclusive prerogative of those who had always found the surgical approach to PD less than convincing. It also involved those who, while accepting that results of the trial were disappointing, were nevertheless still convinced of the value of neurotransplantation as a treatment for PD. Thus, for the Network of European Central Nervous System Transplantation and Restoration (NECTAR), a powerful professional association in this domain, the severest criticism was that the trial always was likely to be unproductive and inconclusive because those conducting it were so convinced of the merits of their approach that, just 1 year into the trial, they offered the treatment to many patients in the control group (see Nikkah, 2001). The underlying commitments of this alternative position are perhaps best expressed by Eugene Redmond, a neurosurgeon at Yale University, who admitted quite candidly that 'the outcome of the first randomised, double blind, controlled study challenged the idea that dopamine replacement cells can cure Parkinson's Disease', but then asked 'were the earlier animal studies and clinical reports wrong? Should we give up on the goal?' and answered his seemingly critical questions with a resounding 'no' (Redmond, 2002: 457; see also Storch and Schwarz, 2002). Pierre Cesaro, a key member of NECTAR, argued even more explicitly that the neurosurgical approach to the treatment of PD '*deserves* new clinical trials' (Cesaro, 2002: 143; emphasis added).

In sum, while the NIH trial aimed to close the controversy over neurotransplantation, it in fact ended up re-initiating and re-articulating a debate that has structured the field for over two decades, between those who support the approach and those who object to its rationale, methodology and ethics. While the latter insist on the absence of any evidence for effectiveness of neurotransplantation and question its procedures, the former view these objections as exactly the reason to continue developing both the approach and the methodological robustness of its trials. What is especially interesting about the debate over the NIH trial, however, is how the two groups have harnessed the results of the trial either to promote or to deter research on the therapeutic uses of stem cells. In this second debate, we can observe both how proposed therapeutic uses of stem cells articulate a particular configuration of the 'self', and how this configuration brings into view a key absence in all discussions about the nature and consequences of PD.

NEUROTRANSPLANTATION, STEM CELLS AND 'SELF-REPAIR'

After the publication of the results of the NIH trial, in early 2001, positions and discussions over its likely impact on the future development of stem cell technology rippled through various arenas. Martin Edwards, the chief executive of ReNeuron PLC, for example, attributed the dyskinesias observed in the trial to the uncontrolled growth of the implanted neuronal tissue, suggesting that, rather than relying on heterogeneous embryonic material, more should be done to investigate new ways of producing 'fit for purpose' neuronal implants in the laboratory, from stem cells (see Boseley, 2001). The same line of argument is evident in a running news stream in *Nature*, one of the leading scientific journals in the world, in which it was suggested that 'work with neurons grown from stem cells could offer clues . . . [for the improvement of the neurosurgical treatment of PD] because such lab-derived cells *would* contain fewer impurities than fetal tissue' (Check, 2003; emphasis added. See also Meek, 2001.). The uncertainty about the possible outcome of this endeavour, which is embedded in the last statement, contrasts sharply with the unambiguous assertions on the uses of stem cells to treat neurodegenerative diseases such as PD that are deployed in the wider, public debate over stem cell technology.

Interest in the neurosurgical applications of stem cell technology has grown extremely rapidly since the first announcement that these cells can be multiplied and differentiated *in vitro* (see Kirschstein and Skirboll, 2001). Such interest is motivated by the hope that the ability to design cells for degenerating or lost tissue might bring about a cure for key diseases in advanced western societies, affecting the vascular and nervous systems of an increasingly elderly population (see Prins, 1998). Significantly, however, some of the most visible supporters of stem cell research have been the much younger actors Christopher Reeve and Michael J. Fox. While the former, up to his death in 2004, was paralysed from the neck down as a result of an accident that damaged his spinal cord, the latter has been diagnosed as suffering from the early effects of PD (King, 2000; Haber, 2004. See also Brown, S. E., 1996.). Like Reeve and Fox, the latter of whom has now established his own charitable foundation for the promotion of research into the treatment of PD, most supporters of stem cell research suggest that research on the more specific biochemical processes by which stem cells differentiate and specialize is directly related to the development of effective therapies for neurodegenerative diseases such as PD. Although arguing from the contrasting point of view, opponents of stem cell research focus overwhelmingly on the troubling, human sources from which stem cells are derived, paying little attention to, and thus corroborating, the claims about the possible effectiveness of stem cell technology. What both sides of the debate seem to ignore is

how the prospect of soon being able to regenerate dysfunctional cellular tissue *in situ* is informed by the experience acquired in clinical transplants of embryonic neuronal tissue, an experience so problematic that it arguably motivates the search for the alternative sources to which Edwards and *Nature* speak in their reactions to the NIH trial (see De Francesco, 2001; Breeze and Wang, 1999).

There is, however, another, usually unspoken, reason why stem cell technology is very attractive to proponents of neurotransplantation, and this involves the threat that neurotransplantation poses for the integrity of patients' personal identity.

Arguably, during the 1970s, neurosurgeons viewed neurotransplantation as an opportunity to redefine their repertoire of neurosurgical interventions at a time when many such interventions – for example, lobotomy, lobectomy and cingulotomy – were attracting considerable public and professional criticism. These psychosurgical interventions were increasingly viewed as unethical attempts to alter patients' personal identity (see Valenstein, 1986; Pressman, 1998). Thus, when Detlef Linke, an iconoclastic neurologist at the University of Bonn, sought to call the emerging field of intracerebral neurotransplantation into question, he linked its approach to just these ethically disreputable interventions (Linke, 1993). Some within the community of bioethicists, and Georg Northoff, a philosopher and clinical psychiatrist at the University of Magdeburg, in particular, have responded to such criticism by denying that neurotransplantation poses any threat to the integrity of patients' personal identity (Northoff, 1996. See also Boer, 1999; McCrae *et al.*, 2003). Insisting on the empirical grounding of ethical discourse, they deny the threat, a denial that rests on appeals to contemporary neurobiological knowledge to question any link between the implantation of biological material in one region of the brain and effects on another location, specifically the complex neural network that is said to sustain 'self' and 'identity' in human subjects. On the other hand, this bootstrapping manoeuvre ignores how psychosurgery and neurotransplantation share the controversial assumption that particular aspects of 'personality' can be located in specific regions of the brain (see Smith, 1992; Star, 1989, 1992). Furthermore, if the distinctions operated by such mapping of the brain have sometimes proved controversial, attempting to maintain a categorical distinction between the 'restoration' and the 'alteration' of personality provides an alternative strategy for differentiation between ethically acceptable and unacceptable neurosurgical interventions (see Northoff, 1996). These rhetorical strategies are particularly evident in Robert Breeze and Marjorie Wang's technical review of developments in the field of neurotransplantation. While they acknowledge common historical origins and epistemic assumptions, they seek to distance neurotransplantation from the like of lobotomy, lobectomy and cingulotomy by associating the latter with 'so-called *functional*

neurosurgery' (emphasis added), despite many of our actors' explicit disciplinary identification with the very same field of 'functional neurosurgery'. Furthermore, they emphasize the difference between 'destruction' and 'restoration' of neural tissue, despite the dependence of 'restoration' on the introduction of *exogenous* neural tissue such that 'alteration' and 'restoration' are in fact conceptually indistinguishable (Breeze and Wang, 1999). Stem cell technology would seem, however, to provide a technical solution to these ethical problems. In fact, the prospect of initiating the 'self-repair' of the brain with undifferentiated and pluripotent cellular tissue would seem to offer a definitive closure of the ethical problem. As a review of investments by the biotechnology industry in the field of neurotransplantation put it, there will have been no therapeutic intervention because 'neural stem cells [will] act as nature's own brain surgeon, psychiatrist, pharmacist, and therapist' (Spalding, 2000; see also Boer, 1999; Grisolia, 2002).

Importantly, the promotion of 'self-repair', motivated by these disparate social and historical considerations, reinforces a vision of the 'self' for which there are identifiable neural boundaries and pathways. We suggest that such reinforcement of the 'self' as the unrelated, yet pivotal, issue for stem cell research points towards an operative absence or blank presence in the debate over neurotransplantation for PD. We therefore return to the debate over the NIH trial.

THE 'REGIME OF HOPE' AND THE 'REGIME OF TRUTH'

From the description given in the sections above, it is possible to see the debate over the NIH trial as evolving around two alternative positions. On the one hand, there are those actors who view the trial as demonstrating the worthlessness of the neurosurgical approach and those who cannot see any justification to continue submitting patients to expensive, hazardous treatments and ethically questionable research practices. On the other hand, there are those actors who view the trial as an example of how not to conduct research, but then point to the success of the neurosurgical approach in animals as reason for continued investment. We suggest that these two positions can be understood as deploying more general forms of argument, which, rhetorically, revolve around the tropes of 'truth' and 'hope'. Significantly, the actors in the debate over the NIH trial, and even within the more broadly defined field of neurotransplantation, deploy these two tropes both repeatedly and in a patterned manner that articulates distinct subject positions. Moreover, the deployment of the two tropes can be analysed further, in terms of distinct orderings and aggregations of actors. These orderings and aggregations constitute the formations in, and through, which these same

actors construct and adjust their positions in debates around the purpose and value of biomedicine. In doing so, these formations generate and perform distributions, defining or embodying a characteristic approach to what might, does, or should, pass from whom to what, under what circumstances (Law, 1994). In other words, they generate and perform distinctive distributions of value, power and agency around the 'patient' or 'sufferer' of the condition under debate (see Rose and Novas, 2000; Brown, N., 2003; Brown, N. and Michael, 2003).

The 'regime of hope' is characterized by the view that new and better treatments are always about to come, being tested, 'in the pipeline'. More specifically, research and development is justified by the promise of finding miraculous cures for debilitating diseases. Such promise entails endless deferrals to stabilize the identity of the therapy, its constituents and effects, deferrals that can be justified in various manners. In the case on hand, these tactical deferrals range from NECTAR's methodological critique of the NIH trial to arguments over the appropriate nature and quantity of embryonic neural material that should be used for more effective transplants. In fact, if the responses to the NIH trial are at all imprinted by the public debates over the sources of the materials used in technologies such as the transplantation of embryonic neuronal material, their traces are to be found in the arguments over the large quantity of foetal material required for successful implantation and the feasibility of xenotransplantation, the transplantation of biological material across species, as an alternative, more copious and less problematic source of implants (Fink *et al.*, 2000; Hagell and Brundin, 2001; see also Clemmit, 1992). The following opposition of 'truth' and 'hope' perhaps best captures the spirit of such deferrals: 'We do not know the truth: there is hope.'

The 'regime of truth', on the other hand, entails an investment in what is positively known, rather than what can be. That is to say, it is characterized by the view that most medical therapies are less effective than claimed, and this involves the constant returning of new and promising approaches to their original claims, their clinical failures and their ethical downfalls. Thus, for some actors, the NIH trial demonstrated what they already knew, namely that neurotransplantation was an ineffective therapy. For others, the NIH trial was populated by a series of biological and methodological problems that were not compatible with the practices of veridicity in contemporary health care (Moreira, 2004). The Blue Cross/Blue Shield's conclusion about the relative merits of the surgical and pharmacological approaches exemplifies this view, which can be then opposed to the 'regime of hope' by a quite different opposition of 'truth' and 'hope'. These actors seem to be saying: 'We know the truth: there is no hope.' It is important to recall, at this point, that, although the pharmacological approach to the treatment of PD might be said to be a 'tried and tested' one, it explicitly entails recognition that death is inevitable.

Around these two recurrent positionings we find different aggregations of actors. The 'regime of hope' draws together new biotechnology companies such as ReNeuron PLC, and the investors in these companies, all of whom depend upon the promise of the neurosurgical approach for a return on their investment of financial capital; there also are neurobiologists, who construct models of degenerative diseases, and the neurologists and neurosurgeons, all of whom have dedicated large part of their careers and intellectual capital to the development of neurotransplantation. Finally, there are charities such as the Parkinson's Disease Society, whose aim is to maintain *all* possibilities of treatment open. The 'regime of truth' aggregates a very different set of groups of actors. Here we find the 'therapeutic reformers' in the NIH who set up and assessed the methodological quality of the trial (see Marks, 1997). There also are health care buyers and insurers, such as Blue Cross/Blue Shield, who are not convinced that the considerable costs of the neurosurgical approach are justified, all too aware of a fundamental difference between 'tried and tested' measures and developments in 'investigational settings' (see Blue Cross/Blue Shield, 2004). Importantly, there also are those pharmaceutical companies worried about the competition from new molecular approaches to the treatment of PD (see Bracco, 2002).

Finally, the 'regime of hope' and the 'regime of truth' differ in the way they imagine and configure the patient. In the 'regime of hope', actors tend to figure the patient as someone who is invested in becoming less entrapped by her or his physical condition; this patient may sometimes be desperate, but is always waiting for new solutions to his or her entrapment. In the 'regime of truth', by contrast, patients are figured as consumers of health care, concerned to compare the relative merits of pharmacological and surgical approaches, by taking into consideration their effectiveness, risk of harm, and cost. In their opposing configurations of the patient, the two regimes both attempt to distribute knowledge and agency between expert and the lay public, and thus to engage, some might say to 'interpellate', the patient's 'self' from different perspectives (Althusser, 1994).

Strikingly, the different subjectivities enacted by the 'regime of truth' and the 'regime of hope' resonate with contemporary debates about embodiment and political subjectivity, which we suggest are important to explore, if we are more fully to understand the predicament confronting the Lambert family.

THE 'POLITICS OF LIFE' VERSUS THE 'POLITICS OF DEATH'

When researching the debate over the NIH trial, we progressively realized, perhaps unsurprisingly, that social scientists are not removed observers of the

regimes of 'truth' and 'hope', but active participants in their constitution (Dehue, 2002). Those social scientists who view the neurosurgical approach as another example of unjustified hype surrounding contemporary biomedicine, and maintain that medicine has not in fact changed the way we live since the introduction of basic public health measures in the 19th century, can readily be associated with the 'regime of truth'. For them, the truth is that we have always begun to die the day we were born, and nothing has changed, biological life continuing to be the norm against which politics must be judged. On the other side, we find social scientists either celebrating or worrying about how science is enabling humans to go beyond their supposedly fixed, biological abilities. Their argument is that we are creating the norms of our own life (see Mykhalovskyi and Weir, 2004; Caplan, 2003). What is at stake in this opposition is intimately linked with the important contrast between the perspectives on embodiment and political subjectivity articulated by Michel Foucault and Giorgio Agamben, on the one hand, and Paul Rabinow and Nikolas Rose, on the other.

This link is observable when we interrogate the modes of reproduction of both regimes. The ultimate aim of the 'regime of truth' is closure, each argumentative move returning to its point of origin, to the original question, to the truth of the matter. As such, it rests on the representation of the state of affairs as it is now, enacting a regime in which the collective is organized around the norm of life, *as it is* and *always has been*. Agamben usefully articulates the full implications of such organization by questioning the extent to which Foucault's labelling of the modern link between embodiment and political subjectivity as 'biopolitical' is in fact a misnomer. For Agamben, 'biopolitics', the productive deployment of the known generative powers of life to regulate and manage political existence, rests on the production of a form of being that is endowed with no potential and that is in suspension between life and death, 'bare life' (Agamben, 1998; see also Foucault, 1990: 150–9). The most vivid and relevant exemplification of this pivotal concept are the 'brain dead', who are biologically 'alive', but socially and juridico-politically 'dead' (Agamben, 1998: 160–5; see also Lock, 2002). As such, the 'biopolitical' is better understood as a 'politics of death', a 'thanatopolitics'. The main resource for the 'regime of hope' is instead capital, whose reproduction demands a belief in a future rather than a resignation to, or an investment in, the present. The future, rather than the past, is this regime's distinctive temporal orientation. Continuous opening of action, with no point of return, is its strategic aim. The 'regime of hope' thus enacts what Rabinow and Rose have called the 'politics of life', a mode of existence characterized by the endless possibilities of humanity as it finally comes to terms with its embodiment. Again, the most vivid and relevant exemplification of this understanding is the emerging figure of the 'neurochemical self', deeply enmeshed in a world where the staid, historical boundaries between

'nature' and 'culture' are everywhere shattered (Rose, 2003. See also Rabinow, 1996; Rabinow and Rose, 2003).

These two contrasting views on embodiment and subjectivity powerfully resonate with differing views of the relationship between the neurosurgical approach to PD and stem cell technology, particularly in relation to the question of 'self-repair'. If the 'politics of death' seems more aligned with a critique of the suspension of human life entailed by stem cell 'culture', much, as Agamben would put it, in the same way that concentration camps operated, constructing the 'self-repairing' body might be understood as marking the achievement of the alignment that Rabinow and Rose imagine, and it must necessarily be 'imagined', given the temporal structure of the 'regime of hope'. In sum, in the debate about the character of contemporary political subjectivity, the opposition of 'thanatopolitics' and 'biopolitics' beautifully encapsulates the struggle that contemporary biomedicine rehearses over human subjectivity.

QUESTIONING 'SELF-REPAIR': A TECHNICAL INTERLUDE

Because we have argued that 'self-repair' sustains the boundary between the 'politics of life' and the 'politics of death', we would now like to draw attention to two problems concerning the goal of 'self-repair', which, if we are to credit the network of citations linked to the final report on the NIH trial that we generated through MEDLINE, on 20 February 2004, would appear to be recognized within the field of neurotransplantation itself.

The first problem is how best to understand the loss of control over motor function. One position draws on a dopaminergic understanding, whereby PD is defined as a malfunction of the physiological systems controlling the production and distribution of dopamine. The effectiveness of the neurosurgical approach is then determined, first, by the relative success in implanting the embryonic material, second, by the increased uptake of dopamine, as measured by positron emission tomography (PET), and, third, by the correlation between the first two and post-operative motor control (see Figure 3). The latter is usually assessed by standardized tests such as the Unified Parkinson's Disease Rating Scale, which measures 'finger dexterity, supination-pronation, foot tapping, and "stand-walk-sit"' (Kopyov *et al.*, 1996: 327; see also Price *et al.*, 1995; Sass *et al.*, 1995).

While the first two criteria were initially distinguished from the third one in terms of 'therapeutic' versus 'clinical' effects, presumably due to doubts about the causal relationship between the degeneration of the *striatum* region of the brain and motor control, the distinction was gradually relaxed in the wake of increasing evidence that successful grafting led to some improvement

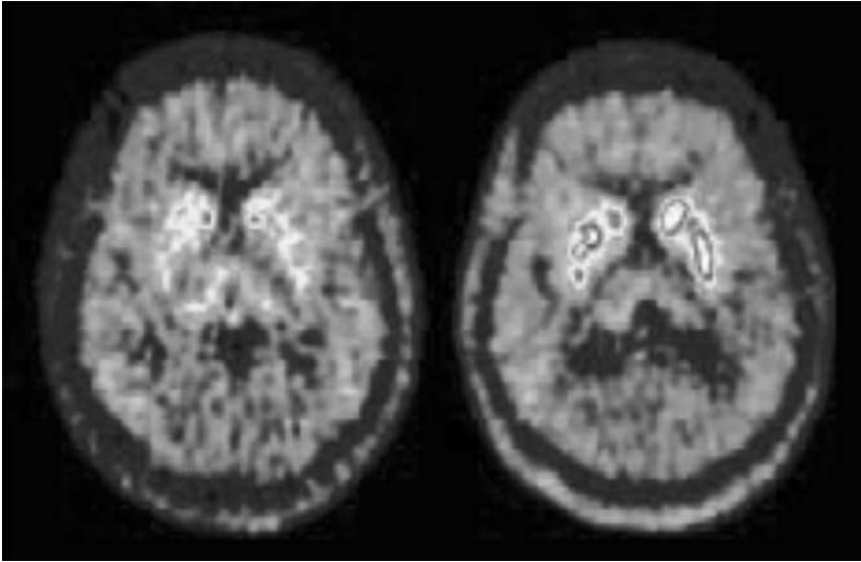


Figure 3 PET scans before (L) and after (R) implantation (see also Dumit, 2004).

Credit: Medical Research Council Clinical Sciences Centre.

in motor control. The relaxation was never total, however, perhaps betraying continuing uncertainty about the dopaminergic definition of PD (see Lindvall *et al.*, 1989; Peschanski *et al.*, 1994; Kordower *et al.*, 1995). In fact, even before the NIH trial was closed, Ivar Mendez, director of the Neural Transplantation Laboratory at Dalhousie University, and his two students, Arun Ramachandran and Lynsey Bartlett, observed that while ‘many transplant recipients obtain *clinically* useful symptom relief . . . in all cases *functional* recovery is incomplete’ (Ramachandran, Bartlett and Mendez, 2000: 243; emphasis added). This further taxonomic complication might suggest that Mendez’s position is closer to the definition of PD offered in the Blue Cross/Blue Shield report which includes a range of psychological symptoms whose causal relationship to motor control is left open, perhaps ‘because the degenerative nature of Parkinson’s Disease is not restricted solely to the dopaminergic systems’ (Blue Cross/Blue Shield, 2001: 1).

Strikingly, however, Mendez has recently suggested that a better way forward for the neurosurgical treatment of PD may be to insert dopaminergic implants not just in the *striatum*, but also in the *nigral* region of the brain (Mendez *et al.*, 2002; see also Hagell *et al.*, 2002). Mendez thus reasserts the importance of the dopaminergic definition of PD, but also begs questions about the cerebral localization of PD. It is important to note, moreover, that this answer is not motivated by criticism such as that voiced by the Blue Cross/Blue Shield Center, but is instead generated by an altogether different

'truth-making engine' best exemplified by NECTAR. This said, the second problem is that, even disregarding the difficulties confronting the dopaminergic definition, so vocally championed by NECTAR, experimental controls are not easily established. As Paul Morrish, Guy Sawle and David Brooks, from the Medical Research Council Cyclotron Unit at Hammersmith Hospital, noted while the NIH trial was in progress, 'Parkinson's Disease has a widely variable rate of progression', so that linking its stage of development to changes in dopamine levels is an 'insufficiently sensitive' diagnostic tool (Morrish, Sawle and Brooks, 1995: 597; see also Sawle *et al.*, 1992; Remy *et al.*, 1995; Rinne *et al.*, 1999). Consequently, it has proved difficult to quantify the specific dopaminergic effects of the implants in the context of the overall, continuing degeneration of the *striatum* (Piccini *et al.*, 1999). More importantly, however, the distinction between the dopaminergic effects of the implanted material and the degenerating *striatum* would seem to betray the notion that the successful implantation of embryonic neuronal material is a step towards the goal of 'self-repair'. If this is simply a matter of temporal sequence, whose horizon is the disappearance of any difference between exogenous implants and endogenous tissue, it is worth noting that Warren Olanow, at the Mount Sinai School of Medicine and a leading figure in the field of neurotransplantation, has disputed that the dyskinesias, the uncontrolled movements, observed in the treatment group in the NIH trial were due to an unexpected overactivity of the implanted tissue, and has argued that they may instead have been due to an immune response, which could not be excluded because those involved in the trial did not use any immunosuppressants (Olanow *et al.*, 2003).

In the light of these above two problems, neurotransplantation remains closer to the engineering of a heterologous remedy, not fundamentally different to the pharmacological treatment for PD, championed by the Blue Cross/Blue Shield Technology Evaluation Center, than to achieving the autologous 'self-repair' of the brain promoted by the biotechnology industry, which foresees 'neural stem cells [becoming] nature's own brain surgeon, psychiatrist, pharmacist, and therapist'.

QUESTIONING 'SELF-REPAIR': A THEORETICAL EXCURSUS

If, up to this point, the regimes of 'hope' and 'truth' seemed to be two diametrically opposed versions of the values of biomedicine, through the notion of 'self-repair' and the debates over its technical problems it is possible to see how these two regimes are in fact predicated on each other. Again, it is through the resonance between the debates about PD and those about the

relationship between embodiment and political subjectivity, that it is possible to understand how the interlocking of the two regimes is mediated through the manner in which they imagine and configure the 'self'.

In the context of advancing a 'politics of life', Paul Rabinow has opposed Michel Foucault's 'will to knowledge' with a 'will to experiment', which he characterizes as 'an experimental mode of inquiry . . . where one confronts a problem whose answer is not known in advance rather than already having answers and then seeking a problem' (Rabinow, 1999: 174. See also Rabinow, 2003; Foucault, 2000). In so doing, however, Rabinow overlooks how any experiment always is simultaneously located within two distinct temporal frames. On the one hand, it is orientated towards a future event, such as the stabilization of the neurosurgical approach to the treatment of PD and the realization of all that it promises for the future of humanity. Such orientation towards the future can be said to be the distinctive temporality of the 'regime of hope'. Its strategy is maximizing. Such maximizing, and therefore potentiating, orientation, whether practical, as is the case with the exponents of neurotransplantation, or philosophical, as is the case for the 'will to experiment', must be necessarily shaped by a deployment of the past and its problems, however. When expectations of the experiment are not met, as was the case in the NIH trial, this is not the end, but it none the less requires reflection and investment in what is known to proceed beyond the present (see Cussins, 1998). In other words, to begin to articulate an alternative approach, it is necessary to retrace the path and reassess what is known. In the case of the 'will to experiment', it entails a reflection on the history of thought about the relationship between embodiment and political subjectivity, from the medieval invention of the 'purgatory' to the modern concept of 'human dignity' (Rabinow, 1999). As such, the process of articulating the future involves engagement with the 'regime of truth', whose practices of veridicity are grounded in the past and are strategically minimizing. From this perspective, the NIH trial represents a return to the point of departure, from which it is possible to elaborate new questions. In this same process, however, the 'regime of truth' confronts the minimal answer with an expanding horizon of possible questions, whose proliferation is none the less necessary to guarantee the continuity of the 'regime of truth'.

If the regimes of 'hope' and 'truth' can then be said to include each other in the very same moment that actors articulate their differences, the relationship between two regimes is best conceived as one of 'mutual parasitism'. As one of us has argued elsewhere:

Mutual parasitism corresponds to a looping process through which different knowledge practices – or regimes – progressively generate their own epistemic resources by translating each others'. In appropriating each other's resources, these knowledges create a composite. This

composite, however, is never truly harmonised as it depends upon the asymmetries and heterogeneities these knowledges can create between them. (Moreira, in press)

In other words, the regimes of 'truth' and 'hope' assume, if they do not in fact require, a single, determinate and common point of reference to which it is possible to return or from which it is possible to depart and differ. Not only do the opposing regimes depend upon this agreed entity, but it also is the common condition of possibility for their continuous disagreement. We suggest that such point of reference is the 'self'.

While any reference to the 'self' is notably absent from the debates over both the goals and effectiveness of the neurosurgical approach, the opposing positions can be understood either as assuming a fixed 'self' that can possibly recover pre-existing potentialities, or as aspiring to re-launch a neuro-physiological dynamic from which a new 'self' can emerge. A similar interlocking opposition is evident in the way in which the regimes of 'truth' and 'hope' imagine the PD patient. While the one imagines a patient who is sometimes desperate, but always waiting and ready to test new and promising, but untested, solutions to her or his situation, the other imagines a patient who is concerned to compare the positively known merits of alternative approaches to forestalling his or her demise. Strikingly, this same commonly centred opposition is still more sharply evident in Agamben, Rose and Rabinow's reflections on embodiment and political subjectivity. For the latter two, the contemporary, embodied 'self' is to be understood as so constantly under erasure as to become increasingly synonymous with 'life itself' (Rose, 2001). For Agamben, this equation, which he labels 'bare life', undoubtedly is deeply troubling, but, paradoxically, it also is, to use Michel Foucault's famous phrase, the key to 'counter[ing] the grips of power' (Foucault, 1990: 157. See also Agamben, 1999a.).

In sum, the composite of the regimes of 'truth' and 'hope' constitutes and maintains the existence of the 'self', both as the ultimate truth and the greatest hope. In this process, the 'self' becomes unavoidable, confirmed at every turn of the debate, progressively established as the only path for public engagement and the main obligation of the subject. In sum, the 'self' becomes the one and only vehicle of subjectification.

WHO IS ALFRED?

We opened the paper by asking: Why is Alfred not interested in getting better? Why will he not at least admit to the hopelessness of his situation? We seem, however, to have failed to answer these questions. In fact, if anything, our argument leads to the view that Alfred's disengagement is

unintelligible. How are we to understand Alfred's disengagement from both the 'regime of truth', which would require him to recognize the hopelessness of his situation and to make suitable arrangements in this light, and the 'regime of hope' advanced by the Axon Corporation? How are we to understand his non-engagement with the two versions of 'self' proposed by the regimes of 'truth' and 'hope', equally represented by the other four members of the Lambert family? How are we to account for his refusal, his very absence? In other words, how are we to understand obscurity, dependent as we are upon the justificatory frames that actors offer to us to understand their worlds? Michel Callon and Vololona Rabeharisoa have recently formulated this very same question, with regard to Gino, a silent sufferer of muscular dystrophy (Callon and Rabeharisoa, 2004). Confronting such silence, they set out to argue that Gino, as a person, expresses a confrontation between two sets of demands. On the one hand, there are the demands of the public sphere, for the visibility, articulation and debatability of his reasons for refusing any engagement with the world of biomedicine. On the other hand, there are the demands for opacity, non-argumentation and exclusion that would seem to be Gino's way of life. Yet, in attempting to describe and understand Gino's silence, Callon and Rabeharisoa cannot but endow him with a subjectivity, that is, an ability to position *himself* outside the arena of biomedical discourse and techniques. Gino's efforts to make his actions, and, more importantly, *himself*, opaque to others are, at least partly, an *effect* of Callon and Rabeharisoa's very presence and interpellation. Moreover, by attempting to make Gino's desire for opacity visible, Callon and Rabeharisoa are also working against the non-accountability Gino would appear to desire most. This was perhaps inevitable. As Callon and Rabeharisoa note, the social and human sciences cannot but fail to multiply local ways of being, locked as they are in addressing public issues. At the same time, however, Callon and Rabeharisoa also direct our attention to the way in which, as we move towards obscurity and indeterminate ways of being, the ability to position and recognize oneself in action is progressively lost. Such loss is beautifully expressed in Jonathan Frazen's description, in the extract given in the beginning of the paper, of Alfred's momentary experience of disconnection:

... in the instant of realizing he was lost, time became marvellously slow and he discovered hitherto unguessed eternities in the space between one word and the next, *or rather* he became trapped in that space between words and could only stand and watch as time sped on without him. (emphasis added)

Through the literary artefact that is *The Corrections*, and it cannot be otherwise, Franzen attempts to give voice to an experience of transcendence that is beyond words, space and time. In this way, we are able to glimpse both the experience of dis-location and self-lessness, and its obscurity. Yet, in the very

moment in which such glimpse is achieved, it loses its significance because what we glimpse is the emptiness of our own sight. What is left, is a feeling for the precariousness of our own selves, how we, like Albert, can 'slip through' the tightly fitted links between our environments and *ourselves* and not find *ourselves* any more. In returning to clarity and accountability, we realize that this slippage is beyond our control, beyond *ourselves* and beyond words. It happens to us so that we are *not* always, already . . .

POSTSCRIPT: A DIALOGUE

Paolo: *Perhaps*, however, more could be said about the tension between making the experience visible and the obscurities it produces in the very process of representation, because this obscurity is precisely that 'bare life' with which Giorgio Agamben is so concerned (Agamben, 1998, 1999b).

Tiago: But aren't you still attempting to represent obscurity by giving it a name, and describing it as a suspension that produces the very process of representation? I am not sure that is the solution to this predicament. Perhaps what Michel Callon and Vololona Rabeharisoa address is part of a much more general ambition of western philosophy to 'represent' and fix on 'what is', on ontology (Jullien, 2002). Perhaps our ability to represent is predicated upon our realization that there is an unrepresentable, but attempting then to represent this unrepresentable seems to undermine the key tension between clarity/self and obscurity/other.

Paolo: I agree with you totally . . . but . . . why are Callon and Rabeharisoa so taken with, and indebted to, Gino, if not as a figure of the *limit*? I cannot help but recall the following, perceptive historical observation, from Michel Foucault's *Order of Things*:

Man and the unthought are . . . contemporaries. Man has not been able to describe himself as a configuration in an *episteme* without thought at the same time discovering, both in itself and outside itself, at its borders yet also in its very warp and woof, an element of darkness, an apparently inert density in which it is embedded . . . (Foucault, 1970: 326; see also Deleuze, 1988)

I would then want to 'gesture' towards Agamben's and Slavoj Žižek's diagnoses of this situation (Agamben, 2000; see also Žižek, 1999). In other words, I would want to emphasize the historical specificity of the situation in which the 'he' of 'in the instant of realizing he was lost, time became marvellously slow and he discovered hitherto unguessed eternities in the space between one word and the next, or rather he became trapped in that space

between words and could only stand and watch as time sped on without him' must be said to lose any valence *in itself* and *by itself*. The point of this 'gesture' is that our, dare I say *poetic*, evocation of something about the human that is 'not always, already' should be understood as willing the return of critical practice to something that is not simply the inert medium of discursive machinery, be it 'bare life' or a 'platform' (see Keating and Cambrosio, 2003), to something that causes both the machinery and associated critical apparatus to stutter and splutter. Toward the end of his own life, Gilles Deleuze spoke of this something as 'a life . . .' (see Agamben, 1999c; Palladino, 2003).

Tiago: [Silence]

Tiago and Paolo: [Wry laughter]

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