This paper was first presented and discussed at the Council's June 2006 meeting. It does not reflect the views of the Council or of the United States Government.

# A TRANSPLANT RECIPIENT AS PATIENT AND RESEARCH SUBJECT EXPLORING THE ZONES OF CORPOREALITY

## BETWEEN LEIB AND KÖRPER

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Presented before the members of the President's Council on Bioethics Washington, D.C.

June 22, 2006

It is true that this famous philosopher made many mistakes, as nobody denies; but he understood animal nature and was the first to demonstrate perfectly that animals were mere machines. After such an important discovery which implies so much wisdom, how can we, without ingratitude, not pardon all his errors.

Julien Offray de la Mettrie

Machine Man

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### I. Introduction: The Participation of Human "Subjects" in Research

In the U.S. Federal Common Rule, that in 1991 consolidated all federal regulations governing the protection of human subjects research, as well as in the Code of Federal Regulations (principally NIH-Title 45 CFR 46; FDA-Title 21 CFR 50 and 56) that among other things governs research involving the participation of "human subjects" of research, a 'human subject' is defined: "... a living individual about whom an investigator ... conducting research obtains (1) data through intervention or interaction with an individual, or (2) identifiable private information." The term 'subject', however, has at least two senses which are important to distinguish in discussions concerning the use of human subjects in clinical research: (1) the 'grammatical' or 'impersonal' and, paradoxically, the 'objective' sense and (2) the 'personal' or 'truly subjective' sense. The grammatical sense simply means that linguistically we refer to the person participating in the research in the first person singular, 'I', but in fact he or she is not construed as the subject in the real, personal sense.

As Dr. Otto E. Guttentag critically observed, "Every effort is made to depersonalize him and to eliminate every subjective factor." This depersonalization, however, is

easily understood. Researchers can plausibly claim to be interested only in a single, narrow dimension of the patient-subject, and not in his or her entire being. In any case, they might add, with hundreds, indeed thousands of subjects, it's simply unrealistic to imagine that researchers are even capable of appreciating the individuality and humanity of each patient-subject. Laypeople will regard this justification and excuse as "perfect common sense."

What laypeople may fail to notice, however, is that the term 'subject' refers to the person as an object of the researcher's gaze, the reified human being from which (rather than whom) the researcher intends to abstract data and/or identifiable private information, under experimental conditions wherein the individuality, the very humanness of a human being is deliberately set aside or calculated out in order to free the essential, narrowly defined dimension or element of study from "confounding" variables, such as individual variance. Nevertheless, when using human beings in biomedical and behavioral research (who require protection 3) the 'subject' should be regarded as a self-conscious, rational, emotional, and free agent. In engaging the "experimental physician" the subject is capable of free and informed consent. In agreeing to join the researcher, subjects engage in activities which researchers have persuaded them will, in time, prevent disease and premature death - to improve humankind's lot; to overcome or postpone the essential infirmity inherent in the human condition by acquiring and applying generalizable knowledge. There are, however, "rules of engagement," of which protection of the reified subject is primary; but which have conceptual and semantic bases on which physicians as researchers should be firmly grounded. Otherwise Guttentag's judgment will be sustained: every effort to depersonalize the subject and to eliminate every subjective factor will dehumanize both researcher and subject.

An additional problem here, however, is that 'subjective' is usually employed pejoratively by natural/medical (though not social) scientists, who fail to appreciate that the personal use of the term 'subject' refers to a being "capable of both elaborating the

world . . . and making sense of it - making what is there conceptually understandable." 
Furthermore, the dual-sense of 'subject' has, as we shall recount, its counterpart in a dual sense of 'human body'.

Various authors have called attention to the generally unacceptable practice of "invading a person's body," even citing laws of assault - an actionable wrong to interfere bodily with another person without his/her consent. 6 Indeed, it is not uncommon to read that "the arbitrary use of people in experiments is incompatible with respect for human dignity." In the "Statement by Committee Member Jay Katz" at the end of the Final Report of the Advisory Committee on Human Radiation Experiments, published in 1995, Dr. Katz indicates that patient-subjects must agree, that is, give permission or provide an informed consent for any "invasions of mind and body." 8 Indeed, the Final Report quotes a telling remark from one respondent: "... I don't read all this fine print and all this stuff and so forth. The lady said that we would like to experiment on your body to see what can be done . . . and it's to help me and so far, so good . . . . Elsewhere Katz, underscoring the "rights of subjects," distinguishes "person" and "body" (physical integrity) that must remain "sacrosanct." <sup>10</sup> Further, Katz distinguishes physical and psychological injuries from what he calls 'dignitary injuries' 11- often indicated in the extant literature by the more awkward but also more accurate expression "wronging persons" (not subjects) - and he cautions us of the ever-present danger of "too relentless a pursuit of knowledge" at the expense of the welfare of what he, too, calls "patientsubjects." 12

Thirty-three years ago, in his *Human Guinea Pigs: Experimentation on Man*, M.H. Pappworth attacked what he took to be the ludicrous dehumanization and disvaluation of patients' emotions and feelings, denoted in expressions like "clinical material" of (say) cardiac catheterization research. Indeed, it's not unusual to learn from respondents to recent surveys, that laypeople bring very little with them to the topic of biomedical experimentation; they know very little, and much of what they believe they know is not

true - even their vocabulary is apt to be very impoverished. Time and again, they take recourse in the term, 'human guinea pig,' which invariably is encumbered with negative connotations. As a result, they are skeptical of participating in scientific studies or investigations, because they don't want to be guinea pigs - mere grammatical subjects or bodies to be invaded. Interestingly,

When asked to explain the term *experiment*, patients often invoked the term *guinea pig* to convey the sentiment of being the "victim" of an experiment. For example, one respondent, when asked to define the term *medical experiment*, said "That's where you get down to the human guinea pig... where they may be injecting medication or whatever they want to inject in someone and watching them for a reaction."

Another respondent, for whom no cure was available, put it cryptically: "Everything is experimental, they don't know how to cure it." On the other hand, still another respondent favorably endorsed research:

Overall I have to say clinical trials, medical experiments are the only way we're going to find any type of results . . . because you can . . . practice on guinea pigs, monkeys, or whatever, but the only way you're going to find out if any of these drugs are going to work is you're going to have to do it on a human being.

The Committee also makes the observation that the term 'medical experiment' evokes the most "striking and negative associations" with risky interventions as well as "weird things done to the body": 17

... patients usually said they would prefer to be in a study. It was reported to be the least harmful because it was believed to be the least invasive. In comparison to experiments, which many patients believed involved "trying things out" on animals/and or humans, "studies" they felt, usually entailed gathering information and reviewing paperwork.

The unwarranted importance attached to terminology reflects once again the undeveloped

character of conceptualization and discourse among the lay public.

II. der Leib / der Körper Distinction in Continental Philosophy and Psychiatry

The dual sense of 'human body' to which I alluded is well known to those schooled in Continental phenomenology and existentialism and their psychological counterparts, especially the philosophical writings of G. Marcel, J.-P. Sartre, M. Scheler, M. Merleau-Ponty, and the phenomenologically-oriented psychiatrists like L. Binswanger, M. Boss, F.J.J. Buytendijk and E.W.M. Straus. They all distinguish (though with various nuances) the physical/organic body (Körper) the object of the physician's "gaze" - to borrow a term from M. Foucault - from what M. Sheets-Johnstone calls the "tactile-kinesthetic body," the lived-body (Leib), where the human body is considered in the broader context of relationship-to-the-world, as lived experience, in which bodiliness is a unity, thereby undercutting and not simply denying what philosophical dualists call the 'psychic' and the 'physical'. In other words, a duality of mental and material (or physical) can now be understood as failing correctly to describe the structure of the distinctively human mode of being-in-the-world. The human subject, the "personal I" - from this standpoint - is no longer regarded "as moored in the world of this body." Rather, the very thing that bodiliness makes evident in everyday experience is "their" integration, a pre-objective field in which subject and object are no longer postulated separately. This unified bodiliness reflects the cohesion we experience, as Merleau-Ponty argued in 1945, even at the level of perception. 21 One is no longer bound to obsession with the soul or mind, either.

In mid-18th Century, the physician-philosopher Julien Offray de la Mettrie in his L'homme machine remarked: "I believe thought to be so little incompatible with organised matter that it seems to be one of its properties." To state it even more radically, Leib, the living creature, is already the psychic! Leib is more than a somatic organism, more than a biological datum or object, more than an animated corpse. Hence it follows that it is incorrect as well as inappropriate for biomedical researchers (and

physicians, too, of course), to treat the body as a mere object (though misleadingly called *subject*), pure and simple. It is surely not yet a corpse, though the inanimate thing, not the living person, has been taken as THE objective datum, THE standard, and the lived-body treated as something secondary, a "fragment of the world," a mere side effect. In sum, the body considered as object (what Cartesians called *res extensa*) is derivative; it is inferred from the lived-body or bodiliness as inalienable center - and this we will probably continue to call 'body' or even 'corpse.'

From the standpoint of the physician/researcher, the subject's body is typically construed as a thing-body (Körper); experienced from the standpoint of the potential research subject (or person), however, it is most commonly construed as lived-bodiliness (Leib). Again, speaking metaphorically, the thing-body is bodiliness usually approached from the "outside" by physicians/researchers (though a person can, as numerous illustrative examples of pathology in the extant literature attest, constitute his or her body as "broken tool," foreign, as Unheimlichkeit [unhomelikeness, uncanny] even as an object of hate - as he or she during illness experiences it to "rot" from terminal cancer or become uncontrollable following stroke). In the Final Report, the Advisory Committee quotes a participant who distanced himself from his disease: "I was going to let them make the decision because they were the ones that were watching the cancer . . . ."

This "distancing," though to some degree experienced by everyone, is found in exaggerated form that is universally regarded as pathological.

In anosognosia, where patients no longer recognize their own specific body parts, this is not explained by appeal to so-called psychological "denial." Rather, the patient's body's parts, before the illness, typically have been ready for action, were at his disposal as he remained open to various types of acts for which his limb would be needed. When, in anosognosia, the physician holds the patient's arm in front of him, the patient says that it belongs to someone else; it's not his arm. In such cases, the patient's body has become Körper, a foreign object, a radical transformation of his corporal schema. The

physician-researcher may also apprehend the patient-subject's body as immobile, an object to be scrutinized; in the limiting case, on the other hand, the medical examiner properly takes the corpse (not Körper) on the dissecting table as the *object* of study.

The lived-body, however, is bodiliness, NOT "embodiment," which refers to "the way in which people experience and inhabit their bodies, and the way in which these bodies incorporate and express social information."

Here it's important to be cautious in the use of technical terms that have become incorporated into everyday speech; otherwise I, too, could be guilty of inadvertently retaining a shadow of Cartesian dualism while systematically rejecting it. For it's a subtle sleight of hand to leave the impression that the lived-body is, as Sheets-Johnstone observes, "superfluous pulp" - particularly easy at a time when the neurosciences that focus on brain and CNS research are in the ascendancy and *Pulp Fiction* in vogue!

Thus we must begin anew, "with a fresh analysis of the experiential dimensions of existence ...," as Sheets-Johnstone admonishes, since 'embodiment', she observes insightfully, continues the insidious Cartesianism where the self is conceived as "packaged in the flesh," and we once again are forced to ask: "What's the self or mind that's embodied?" Thus it is incoherent to continue to speak of an *embodying* body *and* an *embodied* subject - they are "conceptual misassignments." As she warns:
"Embodiment in such instances appears to be a matter of having one's metaphysical cake and eating it too, but with a forked tongue - not to malicious but to inadvertent effect."

Furthermore, medicine functions on the basis of a dualistic metaphysical presumption concerning the "mind-body relation," but the lived-body *is* bodiliness - the person, the entire creature, experienced from the "inside." This, one might say boldly, is what is most distinctive about the human condition - the body is wholly "psychic"; there is nothing *behind* the body. However, one's own bodiliness is never really available, for example, to sight.

Suppose I could arrange one eye such that it could look into the other as the latter was

directing its glance upon the world (as Sartre suggested in 1943 in *L'Etre et le néant* 30). Then although I would see the eye that sees, I would not "see the seeing," for the seeing in its subjectivity is never itself observed. The eye-as-seen is the eye as the agent of sight. Generalizing: to be human is to experience bodiliness, the center of lived, motile experience; yet at the same time human beings are typically construed as thing-bodies among other things in a unified, experiential continuum. The actual or lived-body, then, is never simply an object; I can only experience it through my own center, my "centricity" - to employ Marjorie Grene's term describing a primary character of living creatures. But if one insists on using the term 'mental', then it should be clear that it does not denote something hidden but "is palpably observable in the flesh." So the potential research subject's body is not to be assigned entirely to the world of objects, though it can, of course, be regarded as an object of physiological research by investigators. But having said this, we have only exposed an important problem, not resolved it. Let me explain.

## III. The Zones of Corporeality

What precisely is the process, that is, can we describe the process whereby a human being (e.g., a person who is asked temporarily to give permission to researchers and physicians to be treated more like a thing) is able to initiate and assume what I shall call a "two-directional, self-transforming" process? In one "direction" and at one moment experiencing a transition from (1) the zone of motile lived bodiliness (*Leib*) to (2) an intermediate zone of the lived-body thing (*Leibkörper*) then, at another moment, transition to (3) another intermediate zone of the lived thing-body (*Körperleib*), and finally (4) radical detachment, become an "absent" lived-body, a living object (*Körper*). Then, reversing the process: from (4) to (3) the zone of lived thing-body (*Körperleib*), returning through (2) the zone of lived-body thing (*Leibkörper*) to (1) the true center of one's experience - lived bodiliness (*Leib*)? Indeed, are there four (1-4) modes of anthropos body-being here? What I have "in mind," if it is initially, accurately described

as a "two-directional process," may be noted as follows:

- (1) Leib (2) Leibkörper (3) Körperleib (4) Körper

  [unrealized limiting case until death]
- (3) Körperleib (2) Leibkörper (1) Leib

## IV. Implantation Medicine: Four Types of Prostheses

To articulate further the four-fold uni-directional description noticed above ("zones" 1-4), it might prove useful to explore in some detail a single patient's medical crisis that was at once long-term clinical treatment and, at times, a clinical research protocol using a single "subject." Thus there's one person: a patient-subject, who in the case to be described, survives a medical crisis (with his family's unconditional support).

But before explicating in detail what I hesitate to call "the case" of Ed Linz - whose therapy virtually "exhausted" the U.S. medical armamentarium available at the time of his illness, since he received numerous pharmaceuticals, surgically implanted devices, and, in the end, a human heart transplant - I believe it will be helpful to review a fourfold, anatomically organized scheme of prostheses (defined in the OED as "that part of surgery which consists in supplying deficiencies [1706] . . . and that give additional power [1902]"). It is useful because the patient-subject's lived experience includes an unusual experience (not always made "cognitively" thematic), i.e., during surgical implantation of devices, he "allowed" his body, or sometimes only its parts, to become Leibkörper or Körperleib. At such times, he did not "live in" (1) the pure zone of bipedal, motile, fully-lived bodiliness (Leib), though on a number of occasions he did "live" his lived-body as (4) virtually "absent" (Körper), a mere thing-body for the physician's or surgeon's gaze (say) during implantation.

One can distinguish Four Types of prostheses, where [1] and [2] do not require surgical implantation, though [3] and [4] do:

[Type 1] externally located, removable, e.g., eyeglasses, hearing-aid, intravenous pole, walker, and cane are little if at all incorporated into the corporeal

schema, for one is always aware of their externality; artificial limbs and dentures, however, if they are "successful," are incorporated, thus restructuring the corporeal schema;

- [Type 2] external robotics, e.g., voice commands to external assistive devices are never incorporated, though some robotic assistants have been "personalized into companionship" [portable electrocardiography, attached to Linz, is not usually regarded as a true prosthesis, since it is strictly a monitor and does not replace function an observation I owe to Ian Lawson, M.D.];
- [Type 3] internal implants, e.g., artificial joints and reconstructive breast implants.

  More importantly here, battery-powered ventricle assist devices,
  like cardiac pacemakers and the automatic ICD (Implantable Cardioverter
  Defibrillator) are incorporated and, absent infection or other sources of
  discomfort, eventually recede from awareness; 35 and
- [Type 4] internal, neuro-implants involving "biofeedback loops," usually activated by a surgically placed computerized electrical impulse device, these may well require conscious effort: "I'm going to flex my biceps to grasp the glass with my artificial hand." [These prostheses are generally still in the experimental stage.]

Ed Linz, in the description that follow, underwent Type 1, Type 2, and Type 3.

During a three-month hospitalization he was tethered to an intravenous pole (surely a variant of Type 1); during recuperation he used walker and cane, prostheses that one should not regard trivially, given the importance of the relation between human motility (bipedality), and intellect, first stressed by Aristotle in his "real" definition of man per genus et differentias: "rational biped."

V. Sarcoidosis: Ed Linz's Medical Crisis from the Standpoint of a Descriptive-Psychological Phenomenology
In 1985, at age forty-one, when he retired from twenty years of active duty in the U.S. Navy (having served as commanding officer of a nuclear submarine, and transitioning to a second career as a high-school physics and mathematics teacher and coach of the track team), Ed Linz promised himself he'd have a "thorough physical exam in 1988"; indeed, every three years. He agreed to see a female physician, in her thirties, though a bit anxious about her "trying to stick . . . fingers in various embarrassing places inside my body," but as it turned out she "gave me the best physical examination I had ever received." From "within," Linz (like the rest of us) wondered early on whether, during the examination, he'd become sexually aroused, suffer incredible humiliation, "freeze up," or worse for him - "find it kinky" and enjoy it!

Projecting possibilities on which "zones of corporeality" would predominate during the "physical" examination, Linz notes in standard "Cartesian" fashion, "I felt no different either physically or psychologically." <sup>37</sup> Indeed, in 1991 Linz scheduled another examination that at first yielded what he expected: routine, normal results. But surprisingly the EKG wasn't "normal"; it showed an inverted T wave, suggesting an abnormality in the repolarization of the fibers of the ventricles, and THIS wasn't indicated on the 1988 EKG, so an echocardiogram was ordered. Linz remarks, "I felt no sensation from the actual high frequency sound waves that were mapping my heart." 38 The medical "gaze" from without now fully objectified Linz's body (Körper) and the doctor concluded, having "read" the screen and interpreted the data: "... the right ventricle of my heart was not working well and . . . both my right atriuim and right ventricle were enlarged;" indeed, they continued to enlarge. Heart catheterization was next. Notwithstanding the fact that the heart valves were normal and no blockage was noted in the heart's arteries, the results of biopsies indicated a fatal, though still mysterious diagnosis - "cardiac sarcoidosis" - the first shattering moment with respect to which the "first symptoms . . . appeared in the summer of 1991."

There would be numerous other catheterizations and diagnostic tests. "Identifying

sarcoid," Linz notes, "is not the problem. Determining its cause and finding a cure have been the mystery." <sup>41</sup> In sarcoidosis the granulomas disrupt the normal signal paths of the heart, and the normal signal pumping rhythm becomes erratic; dangerous arrhythmias are the result. "Fortunately" the sarcoidosis was confined to the heart: ". . . it had not spread throughout my body." <sup>42</sup> Here it's important to note that Linz had no awareness or "inner experience" of his disease; indeed, he was a *lanthanic patient* with a "pathognomonic abnormality" in his electrocardiogram. <sup>43</sup> One could say that except for specific medical interventions, e.g., the various tests, he continued to live in the zone of everyday life, lived bodiliness (*Leib*).

In hospital, Linz was often tethered to an intravenous pole [Type 1]. Soon after Prednisone was prescribed (high initial doses that tapered to 15 mg, then down to 7.5 mg daily), Linz agreed to wear his first "prosthesis" around the clock: the Holter Monitor, or dynamic electrocardiogram [Type 2?]. This is a long-term portable, ambulatory EKG, a device that monitors heart function, typically for a continuous 24-hour period. (The patient also keeps a concurrent "log" of daily activities, which is then compared to the EKG readout.) Later, he "carried" a Cardiocare ECG Recorder [Type 2 ?] for ad hoc use during periods of suspected arrhythmia. (Whenever the patient suspects an arrhythmia event, the patient initiates recording and then telephones the recorded impulses to an oncall technician for analysis.) In time, Linz received his first defibrillator, a surgically "installed" prosthesis [Type 3] to shock and, if appropriate, to pace in either of two ways and "override and control" an arrhythmia like supraventricular tachycardia or ventricular tachycardia (VT), i.e., to shock the heart back into normal rhythm in the event of a problem like VT. 44 Already the TV-series metaphor of "bionic man" had taken hold. In time, Linz would "wear" (test?) an FDA-yet-to-be-approved prosthesis [Type 3], an implantable, rechargeable cardiac pacemaker. Though he hoped to benefit from the device, he conceded that the transition to "guinea pig" was complete. . . .

These clinical procedures, surgical implants, numerous electrophysiologic studies, and

nuclear medicine tests like the MUGA (Multi-Gated Acquisition) study to determine the pumping effectiveness of the heart required Linz to continue to assume the role of patient; he did so with extraordinary insight and courage. Indeed, on numerous occasions he felt lousy, or as he modestly put it, not so hot.

The reader of Life Row soon realizes Linz the patient was often, simultaneously, a research subject. The introduction of investigative technology and, later an automatic Implantable Cardioverter Defibrillator (ICD) prosthetic, as part of his treatment, was experimental in the sense that the technology was novel; that, while the primary intention was therapeutic in end-stage disease, knowledge of its effects and effectiveness was very limited. There was also substantial information to be obtained from its use in his case. Dr. Ian Lawson has observed, that "this is similar to 'off label' use, in the same clinical circumstances, of otherwise approved medication. Together, they comprise a class of therapeutic experiment, usually in individual cases, where IRB review would not apply. nor should; but where considerations of the experimental should apply in the type of consent obtained." [personal conversation]. Indeed, the Advisory Committee notes that research is often framed as therapy; sometimes this is a consequence of confusion and at other times the two are simply "inextricably interwoven." 48 In Linz's case, it seems clear that the interventions were primarily therapeutic and conducted by physicians as clinicians; which is not to say that they did not learn nor could not learn more about the therapeutic devices or stratagems. Indeed, every treatment is an individualized experiment, whereby the unforeseeable dimensions of medical care can be defined; whereas a controlled experiment is designed to answer specific questions, i.e., to reject various null hypotheses. Nevertheless, patients often conflate research and therapy. As one physician-researcher observed in the late '50s, from the standpoint of the physicianresearcher: "We're caught in an eternal conflict between being physicians and medical researchers." For our purposes, however, I believe an important principle reveals itself here: The sicker the patient-subject, the more he or she views research as therapy and the more he construes his lived body-thing as an object (Körperleib). Thus, paradoxically, it is during serious illness that a patient is best self-described in the bifurcated language of Cartesian dualism - a mind in a body, a mind and a body. Not only does this principle suggest what may actually "motivate" the transition between zones of bodiliness from Leib to Körper and Körper to Leib, but there is a pragmatic usefulness to patients if they adopt a detached dualism to get them through the unpleasantness of investigation or therapy. Maybe that's the point! But what patients find useful or expressive is no ground for physicians adopting as a system of thought in either practice or research. - a mind in a body, a mind and a body! Moreover, the contrary principle also suggests itself: the more healthy the patient-subject, the less he or she tends to conflate research and therapy and the more the patient construes his or her body as lived thing-body (Leibkörper).

Linz as a subject-patient accepted implantable prostheses (noted by the FDA as "devices"), but these devices themselves were often in the "experimental" stage.

Moreover, at one point, Linz agreed to be the subject of an electrophysiological (EP) study. An EP study includes a procedure, which allows the physician-researcher to study the electrical conduction system of the heart, but in this case it's a "pilot study" with a subject pool whose 'N' is 1, ond one in which the subject is asleep - perhaps an extreme case of "allowing" one's lived bodiliness to become mere thing-body (Körper) for the physician's gaze. Once the physician understands what the patient-subject's heart is doing, there's the possibility of correcting it - in short, finding a helpful regimen. But in Linz's case the results of the study weren't good.

Following a course of Amiodarone (like other cardiac drugs, not particularly "user-friendly," though perhaps a lot less toxic than some other anti-arrhythmics like quinidine), though it had some positive effect to prevent VT, it also had a negative effect on some internal organs. In short, it was eventually necessary to accept an alternate, "permanent" therapy, a safety net: to implant an ICD, an internal battery-powered assist device to monitor the heart rate and assist (shock, sometimes pace) it to return to a

normal rhythm if it went into VT This "shock," he points out, was the worst part of the ICD implant; but it "was never the physical pain, but the immediate fear that my heart would not respond to the shock and I would die immediately." Indeed, Linz, within a year, received an improved ICD model, designed and implanted with the hope of eliminating problems with the earlier model.

The modification of bodiliness that occurs after a month or so, enables the patient fully to "integrate" the ICD, thus modifying what in 1950 P. Schilder (though a dualist) called the body's plastic "schemata." <sup>54</sup> The surgeon told Linz: "you won't even know that it's there." <sup>55</sup> By 1994 an advanced pacemaker, "about the size of a book of matches," was also implanted "in the fleshy area beneath my left collarbone." <sup>56</sup> Linz remarks: "I now had two metal encased computer systems [Type 3 prostheses] inside my body keeping me alive." <sup>57</sup> Furthermore, there was another less invasive procedure that monitored the monitor, so to speak: a radio transmitting device was placed on Linz's skin over the stomach, directly over the box, which "interrogates" the ICD via a laptop computer-type device. <sup>58</sup> Linz reports that at one point he had been "repaired by a laptop" [short-term Type 2 prosthesis?] - he was no longer simply a patient but also a research subject.

His implants remained in him for three years. Here I should mention the fact that his permission, though requested, was not always granted - Linz was no "fully compliant" patient! But eventually he needed a heart transplant, having been "put back," as he says, "into the real world of universal suffering."

Ultimately, following a three-month wait in hospital involving multiple transitions among all four zones of corporeality, a donor heart became available. The prostheses that had been "part of him" were removed during surgery, along with his diseased heart. Linz remarks: his female donor's heart "was now part of me!" Yet the Ordeal base over. Within thirty-six hours post surgery, Linz's body lapsed into a dangerous Adult Respiratory Distress Syndrome (ARDS), propelling him into a three-week period of zone

4 (Körper). During this period, while transitioning from coma to intermittent consciousness, Linz found that the vivid, medication-induced nightmares were preferable to the extreme pain felt during his brief waking periods. "Reality," he recalled, "was far worse than the nightmares!"

What was needed now was a "tincture of time," as one of his many physicians phrased it. In time, the successful transplant, the donor heart, adapted well to its new location, but periodic biopsies and anti-rejection medication became necessities for the foreseeable future. But the transplant operation led to full recovery, part of which required Linz to use walker and cane, the most elementary of prostheses. And lest we forget, following an extended period lying flat on one's back in the ICU, just lifting the body (heft) is a harsh reminder of the body as lived-body thing (Leibkörper): "I could lift virtually nothing. Getting up from a chair was always an adventure." Regrettably, experiences like these have mistakenly been construed as tangible confirmations of Cartesian (mind and body) dualism.

Have we at last arrived at THE critical moment, argument? Can we reconstitute Linz's descriptions of his bodiliness in terms of the four zones of corporeality which we have described in rather general terms? Recall:

- (1) Leib: "I felt lousy," "not so hot." [The surgeon told Linz], "you won't even know that it's [the ICD] there." [My donor's heart] "was now part of me."
- (2) Leibkörper: "I felt no sensation from the actual high frequency sound waves that were mapping my heart." [It] "was never the physical pain, but the immediate fear that my heart would not respond to the shock and I would die immediately."
- (3) Körperleib: "The right ventricle of my heart was not working well and . . . both my right atrium and right ventricle were enlarged." [The sarcoidosis] "had not spread throughout my body." "I now had two metal encased computer systems inside my body keeping me alive."

(4) Körper: [The doctor might] "stick... fingers in various embarrassing places inside my body." [I was] "repaired by a laptop." "I could lift virtually nothing. Getting up from a chair was always an adventure."

VI. Beyond the Standard View of Informed Consent in Research Ethics

A philosophical interest in zones of corporeality or bodiliness, including and "between" Leib and Körper, though central to this essay, should not lead us to ignore the importance of each person's permission, when providing an informed consent to serve as a research subject before actually participating in an experiment, investigation, or study (after all, these words are interchangeable). That is, in addition to the three principal "cognitive" criteria that constitute the standard view of "ideal" informed consent initially indicated in the Nuremberg Code - voluntariness (personal autonomy), mental capacity, and a potential subject's understanding of the information provided by the principal investigator - there is the matter of one's freedom and willingness to "absent" one's lived-body from the everyday joy of painless, motile, fully-lived bodiliness and to "transition" to a thing-body for the physician-researcher's ends, and sometimes altruistically for future humanity, future patients. As Renée Fox remarked over forty years ago, "Many patients conceived of themselves as participating in experiments 'for the good of medical science, and for the humane benefit to others in the future'." On the other hand, there is the serious matter of "therapeutic misconception" where participants in research, especially seriously ill people (no matter how well crafted and qualified the information provided by principal investigators to the contrary) continue mistakenly to believe the regimen of the protocol in which they are participating will yield some relatively immediate benefit to assuage their disease and prolong their own survival - the integrity of their lived-body. Investigators, of course, can easily manipulate and even exploit patients' false beliefs, but there's no reason to assume they frequently and deliberately mislead patient-subjects although they may well understand how useful this delusion of benefit may be to their interests, and may unconsciously refrain from

aggressive efforts to dispel it.

VII. Two Contrasting Weltanschauungen

For the Many, especially when seriously ill and infirm, there's hope and prayer, faith in salvation and eternal life: the hope, also, that medicine will be curative or at least potent enough to postpone death; second, that with abiding faith in the existence of a personal God, and through God's grace, death will not be the end of existence, only of earthly, corporeal existence. [I recall a theologian - no atheist he - who not long ago remarked: "God will kill us all." The audience laughed. The audience also laughed when the film actor, Tracy Ullman, quipped: "I believe in the Holy Ghost, but I'm in no hurry to meet him"; or as the late Joe Louis observed, "Everyone wants to get to heaven, but nobody wants to die."] Although to date no philosopher has proffered an irrefutable argument to prove the existence of a personal God, some claim to have experienced the mystery, and when they did so, in this life, they somehow "transitioned" from Leib to the "edge" of Leibkörper, "returning" through Körperleib to Leib.

For me, THE illustrative example of this Weltanschauung or world-view is found in the writings of Plotinus, a third-century Hellene of our era - a neo-Platonist with a vengeance - who describes his mysterious sojourn to virtual Körper - leaving his body "behind" to identify his Soul with the One Divine, "returning" in time to Leib. Consider the opening lines of The Soul's Descent Into Body - Fourth Ennead, Eighth Tractate:

Many times it has happened: lifted out of the body into myself; becoming external to all other things and self-encentred; beholding a marvelous beauty; then, more than ever, assured of community with the loftiest order; enacting the noblest life, acquiring identity with the divine; stationing within It by having attained that activity; poised above whatsoever within the Intellectual is less than the Supreme: yet, there comes the moment of descent from intellection to reasoning, and after that sojourn in the divine, I ask myself how it happens that I can now be descending, and how did the Soul ever enter into my body, the Soul

which, even within the body, is the high thing it has shown itself to be.

Plotinus' account of his Soul's ascent from and descent into the body (perhaps another illustration of what Drew Leder has poignantly called "the absent body" reflects not only Plotinus' disdain for Matter (in our context the thing-body as limiting case - Körper), but an ontology that is throughout sternly non-worldly. Indeed, even the zone of corporeality (Leib) is nothing more for Plotinus than a prison, and all the "heavenly bodies," the Cosmos, nothing more than a denigrated "evil empire":

Everywhere we hear of it [the human Soul] as in bitter and miserable durance in body, a victim to troubles and desires and fears and all forms of evil, the body its prison or its tomb, the Cosmos its cave or cavern.

Furthermore, as Matter is absolutely evil (absolute deficiency of good) and vice and body are one, he adds:

For weakness in the body is not like that in the Soul; ... the weakness be in the fallen souls, neither cleansed nor clean; and in them the weakness will be not in any privation but in some hostile presence, like that of phlegm or bile in the organs of the body. ... This is the fall of the Soul, this entry into Matter: thence its weakness. ... Thus the cause, at once, of the weakness of the Soul and of all its evil is Matter. ... The Soul would never have approached Matter but that the presence of Matter is the occasion of its earth-life.

Thus the human body in its "earth-life" is like dirt or mud, whereas the Soul, "the high thing," is like a perfect diamond. The contemporary, abiding hope in medicine reflects humanity's struggle with the "dirt and mud" - acute and chronic illness, intractable pain, suffering, dying - the finitude of human existence, premature death, "death within life itself." But there's an entirely different Weltanschauung, one that stands the Platonists' hierarchy of Being on its head.

In this Weltanschauung, soul is just another name for the body. The essence of this Weltanschauung is cryptically noted by Wittgenstein in his Philosophical Investigations:

"der menschliche Körper ist das beste Bild der menschlichen Seele" ["The human body is the best picture of the human soul." <sup>79</sup>] Perhaps it's time to think past the insidious influence of Platonism and to reject its more modern instantiation, disclosed in the writings of the Cartesians, I mean "Cartesian dualism" (res extensa et res cogitans, the physical or material and the mental, body and mind, body and soul, brain and mind, body and spirit) which, it's important to note, is not the same as rejecting the metaphysics of René Descartes, the philosopher to whom La Mettrie alluded in the quotation that opened this essay - the same philosopher, by the way, who in his private notebook wrote "larvatus prodeo" - "I come forward in a mask."

#### VIII. Conclusion

A final word: true wisdom, or at least the quest for the consolation of philosophy, should, I believe, involve an accommodation with one's lived bodiliness, no longer construed as a "prison," a "tomb," or the "baser self imprisoning mind" that is concealed from the world by some superfluous pulp. As the late Samuel Todes observed in his "Anticipatory Postscript," "We originate in the self-actualization of our perceptive body in the actual world"; indeed, we "die the death of reason" in the idealization of a "bodiless mind." But if we ever get it right, we shall rediscover that thanks to our motility, our sense of being an individual self-moved mover, there is one and only one actual world, the field of all our fields of activity. In time, we should find that we remain in the original world as an "interiorized life of a rooted person..."

Furthermore, we would do well to adopt a modest view of the power the human intellect or reason can play in any life (including the medical scientists' search for generalizable knowledge that requires the participation of human research subjects) and, in the end, acknowledge the possibility of the abyss - admittedly the deeply unedifying demands of one's "eternally" mortal frame, one's corporeality, which, I observe, the Many are still, sadly, unable to celebrate.

#### **ACKNOWLEDGEMENTS**

I take this occasion to offer my appreciation to Ed Linz, who I was fortunate to meet in Boston on December 7, 1999, while attending PRIM&R's (Public Responsibility in Medicine and Research) Twenty-Fifth Anniversary Conference: 1974-1999. Ed presented an outline of his story (published by him as *Life Row* in 1997) that proved intriguing and enlightening and without which I could not have written this paper. Subsequently, Ed graciously reviewed a penultimate draft, adding a number of subtle and valuable observations. I've done my best to recount accurately and authentically the salient medical aspects of Ed's courageous and compelling story.

I also thank my friends and colleagues, Professor Thomas Halper and Dr.Ian Lawson, for reading the penultimate draft of this essay. Their constructive critique is always on the mark, insightful, and helpful in completing the final draft - for which, of course, I am entirely responsible.

#### NOTES

- J.O. de la Mettrie, Man Machine and Other Writings [1747], trans. & ed. A. Thomson (Cambridge, U.K.: Cambridge University Press, 1996), p. 35.
- M.H. Pappworth, Human Guinea Pigs: Experimentation on Man (Middlesex, U.K.: Routledge & Kegan Paul, 1967), p. 23.

- 3. This approach was not germane to the work of natural scientists like Galileo Galilei, who were free of state regulation designed to protect human subjects (I leave aside the infamous "Galileo affair" with the Roman Catholic Church) to focus their research on inanimate nature. In *The Assayer* (1623), Galileo describes the task that requires a "natural philosopher's" life-time commitment: "Philosophy [Nature] is written in this grand book the universe, which stands continually open to our gaze. But the book cannot be understood unless one first learns to comprehend the language and to read the letters in which it is composed. It is written in the language of mathematics, and its characters are triangles, circles, and other geometric figures, without which it is humanly impossible to understand a single word of it; without these, one wanders about in a dark labyrinth."
- 4. Pappworth, op. cit., p. 286.
- M. Sheets-Johnstone, The Roots of Thinking (Philadelphia: Temple University Press, 1990), p. 328.
- 6. D.W. Meyers, The Human Body and the Law: A Medico-Legal Study (Chicago: Aldine/Atherton), chap. 4, 1970.
- Advisory Committee on Human Radiation Experiments, Final Report (Washington, D.C.: U.S. Government Printing Office, October 1995), p. 116.
- 8. Ibid., p. 849.
- 9. Ibid., p. 742.
- 10. N.M.P. King, G.E. Henderson, and J. Stein, "Regulation and Relationships: Toward a New Synthesis," in N.M.P. King et al. (eds.) Beyond Regulation: Ethics in Human Subjects Research (Chapel Hill, NC & London, U.K.: University of North Carolina Press, 1999), p. 200.
- 11. Although physical and psychological injuries need not be perceived as such by patients/subjects, 'dignitary' injury make be
- 12. Advisory Committee, op. cit., p. 856.
- 13. Pappworth, op. cit., pp. 270, 280.

14. Advisory Committee, op. cit., p. 734. Dr. Jeremy Sugarman (Duke University Medical Center), who as a Senior Policy and Research Analyst to the Advisory Committee, was the staff member with primary responsibility for coordinating the Subject Interview Study, chap. 16, pp. 724-757.

15. Ibid., p. 737.

16. Ibid., p. 733.

17. Ibid., p. 734.

18. Ibid., pp. 734-735.

- 19. J. Bullington, The Mysterious Life of the Body: A New Look at Psychosomatics (Linköping Studies in Arts and Sciences, vol. 190) (Linköping, Sweden: Linköping Studies in Arts and Sciences).
- S. Todes, The Human Body as Material Subject of the World [dissertation 1963]
   (New York & London, U.K., 1990), p. 13.
- M. Merleau-Ponty, Phenomenology of Perception [Phénoménologie de la perception, Librairie Gallimard, 1945], trans. C. Smith (London, U.K.: Routledge & Kegan Paul, 1962).
- 22. de la Mettrie, op. cit., p. 35.
- 23. Todes, op. cit., p.16.
- 24. F. Svenaeus, "Das Unheimhene Towards a Phenomenology of Illness," Medicine, Health Care, and Philosophy, 3(1)(2000), pp. 3-16. Viz., "The Body Uncanny: Further Steps Towards a Phenomenology of Illness," Medicine, Health Care, and Philosophy 3(2) (2000), pp. 125-137.
- 25. Advisory Committee, op. cit., p. 744.
- 26. J. Cassell. *The Woman in the Surgeon's Body* (Cambridge, Mass.: Harvard University Press, 1998), chap. 1.
- 27. Sheets-Johnstone, op. cit., p. 303.
- 28. *Ibid.*, p. 304.

- 29. S.K. Toombs, The Meaning of Illness: A Phenomenological Account of the Different Perspectives of Physicians and Patients (Boston & Dordrecht, The Netherlands, 1992).

  Viz., Svenaeus, "Das Unheimliche" op. cit.
- Being and Nothingness: An Essay on Phenomenological Ontology, trans. H.E.
   Barnes (New York: Philosophical Library, 1956), p. 304.
- 31. Sheets-Johnstone, op. cit., p. 308.
- N.M.P. King, "Experimental Treatment: Oxymoron or Aspiration," Hastings Center Report 25(4)(1995), pp. 6-15.
- 33. Pappworth reminds the reader of Victor von Weizeacher's [sic Weizsäcker] remark, at the end of WW II following the termination of so-called Nazi "experiments": "There is not much difference whether a human being is looked upon as 'a case' or as a number tattoed [sic] on the arm. These are only two aspects of the faceless approach of an age without mercy. . . . This is the alchemy of the modern age, the transmogrification of subject into object, a man into a thing . . . (op. cit., p. 227). Reée Fox's Experiment Perilous: Physicians and Patients Facing the Unknown (New Brunswick, N.J., London, U.K., Transaction Publishers, reprinted in 1998), we should appreciate, was originally published eight years before Pappworth's Human Guinea Pigs. Cf. Experiment Perilous, Note 16, pp. 112-113).
- 34. S.F. Spicker, "Aging and Dependency in a Prosthetic Age: Humanity in the Penultimate Stage of Embodiment," Southwest Journal on Aging 9(2) (1993/94), pp. 41-49.
- 35. Innovative implants of this type continue to proliferate. One illustration: in the news from the Food and Drug Administration reported by Dr. Jane E. Henney, Commissioner of Food and Drugs, in the June 7, 2000 issue of *The Journal of the American Medical Association*, she announced that there's now an implant for chronic nausea: "The FDA has approved an abdominal implant (Enterra, Medtronic Corp, Fridly, Minn) for treatment of chronic, intractable (drug-refractory) nausea and vomiting secondary to

gastroparesis of diabetic or idiopathic etiology" (p. 2779). The device [a term that originally referred to anything between a positive and negative pole - a point I owe to Dr. Wayne Cooper] includes a subcutaneous pocket implant in the stomach together with leads and pulse generator. "The implant's mechanism of action is similar to that of a cardiac pacemaker. . . . One of the two studies of the implant was a double-blind, randomized trial with 33 patients and a primary endpoint of a reduction in vomiting frequency" (p. 2779).

36. E. Linz, Life Row: A Case Study of How a Family Can Survive a Medical Crisis (Spokane, Washington: Exchange Publishing, 1997), p. 12.

- 37. Ibid., p. 13.
- 38. Ibid., p. 18.
- 39. Ibid., pp. 18, 147.
- 40. Ibid., p. 87.
- 41. Ibid., p. 28.
- 42. Ibid., p. 46.
- A. Feinstein, Clinical Judgment (Huntington, New York: Robert E. Krieger Publishing Co., 1967), p.145.
- 44. Linz, op. cit., pp. 125, 138, 148.
- 45. Ibid., p. 152
- 46. Though Linz did not undergo ablation (a procedure that requires the cardiologist to map the electrical system of the heart so corrective burn action can be taken in appropriate areas), it is becoming an increasingly common procedure but at this writing one not accurately classified as "minimal risk."
- 47. Linz, op. cit., pp. 136,153)
- 48. Advisory Committee, op. cit., pp. 737, 748-749. Viz., King, op. cit.
- 49. Fox, op. cit.
- 50. S.F. Spicker, "Research Risks, Randomization, and Risks to Research: Reflections on

the Prudential Use of 'Pilot Trials' "in S.F. Spicker, et al. (eds.) The Use of Human Beings in Research: With Special Reference to Clinical Trials (Philosophy and Medicine Series, vol. 28) (Boston & Dordrecht, The Netherlands, 1988), pp. 143-160.

51. Linz, op. cit. pp. 226; also pp. 64, 111, 149; 113. The surgeon inserts two small screws into the heart and attaches (sews) leads on paddles directly to the side of the heart, and the control box is inserted just under the skin, in the "fleshy area" in the upper abdomen, where it can be easily replaced. At the time, this ICD was classified by the FDA as an "investigational device." Current models are considerably smaller, and the trans-venous leader obviates the necessity for open-heart surgery.

52. Ibid., p. 190.

53. Ibid., p. 137.

54. P. Schilder, The Image and Appearance of the Human Body: Studies in the Constructive Energies of the Psyche (New York: International Universities Press, Inc., 1950), pp. 11-12 passim.

55. Linz, op. cit., p. 112.

56. Ibid., pp. 149-150

57. Ibid., p. 150.

58. Ibid., p. 124.

59. Ibid., p. 149.

60. Ibid., p. 214.

61. Ibid., p. 251.

62. Ibid., pp. 245-274.

63. Personal correspondence, July 26, 2000.

64. Linz, op. cit., p. 263.

65. Ibid., 262.

66. Ibid., p. 283.

67. The Nuremberg Code (1947) states: "1. The voluntary [autonomous] consent of the

human subject [person] is absolutely essential. This means that the person involved should have legal [mental] capacity to give consent; should be so situated as to be able to exercise free power of choice [autonomy], without the intervention of any element of force, fraud, deceit, duress, over-reaching, or other ulterior form of constraint or coercion; and should have sufficient knowledge [information] and comprehension [understand the information] of the elements of the subject matter [the experimental protocol] involved as to enable him to make an understanding and enlightened decision [autonomy]..."

Although all three standard criteria for obtaining a research subject's informed consent is an "ideal" never totally satisfied - i.e., a subject never fully comprehends (mental capacity) the information presented, and is completely uncoerced and entirely autonomous (a point I owe to Baruch Brody) - this in itself seems insufficient grounds for abandoning the requirement.

Furthermore, it should not go unnoticed that the Code entirely ignores the largely non-financial, transaction costs of informing to physician-researchers and of becoming informed to patient-subjects. These costs (e.g., frightening potential subjects so they decide to refuse to participate in research) are so high in contrast to the perceived benefits (e.g., researchers feeling gratified that potential research subjects fully grasp the risks involved), that informed consent often becomes an empty ritual, bereft of real meaning and incapable of serving its stated purpose.

68. B.A. Brody, The Ethics of Biomedical Research: An International Perspective (New York & Oxford, U.K.: Oxford University Press, 1998). Viz. T. Grisso and P.S. Appelbaum, Assessing Competence to Consent to Treatment: A Guide for Physicians and Other Health Professionals (New York & Oxford, U.K.: Oxford University Press, 1998).

69. As Drew Leder has astutely observed, whether the reference is to (i) the body's surface or (ii) the visceral organs that constitute the inner body, "absence" signifies "the

being-away of something." At times, e.g., the body's parts are an "unthematized substratum," only "marginally available." They have not strictly speaking disappeared (they "not-appear"); there is little or no direct or "explicit awareness" of them since they have temporarily receded from "focal awareness" Cf., The Absent Body (Chicago, University of Chicago Press, 1990, pp. 15-16, passim).

- 70. Fox, op. cit., pp. 135, 150.
- 71. Advisory Committee, op. cit., p. 747.
- 72. The reader should not be misled: Nothing discussed here *et passim* should be taken to suggest that I've been addressing what's been called by psychologists and others, like H.H. Price, an 'out-of-the-body experience' (there are at least two types of such experiences); where, for example, the subject seems to himself to observe his own physical organism from outside, as if it were the body of someone else. As one subject remarked: "... I was outside my body, but it wasn't me, as I knew myself. I was just an impersonal being watching an unknown person sitting there. ... During the 'detached body' experience I felt as though I was a distinctly different person looking at myself, in a sort of elevated floating state." *Cf.* C. Green, *Out-of-the-Body Experiences*, Foreword by H.H. Price (Oxford, U.K.: Institute of Psychophysical Research, 1968), p. 98.

  73. Plotinus [ca. 266 A.D.], *The Enneads*, trans. S. MacKenna, 2nd ed. revised, B.S. Page
- (London, U.K.: Faber and Faber, 1956), IV, 8.1.
- 74. Leder, op. cit.
- 75. Plotinus, op . cit., IV.8.3.
- 76. Ibid., I.8.14.
- 77. Svenaeus, "Das Unheimliche" op. cit., p. 8.
- 78. S.F. Spicker, *The Philosophy of the Body: Rejections of Cartesian Dualism* (Chicago: Quadrangle Books, 1970).
- L. Wittgenstein, Philosophical Investigations (New York: Macmillan, 1953), Part IV,
   Section 178.

80. Perhaps the "mask" is Descartes' allusion to his so-called "dualism." In *Machine Man*: la Mettrie remarks: "For whatever he recounts about the distinction between the two substances, it is obvious that it was only a trick, a cunning device to make the theologians swallow the poison hidden behind an analogy that strikes everyone and that they alone cannot see." He continues: "For it is precisely that strong analogy which forces all scholars and true judges to admit that, however much those haughty, vain beings - who are more distinguished in their pride than by the name of men - may wish to exalt themselves, they are basically only animals and vertically crawling machines" (*op. cit.*, p. 35). *Viz.*, E. Anscombe and P. Geach (eds.) *Descartes: Philosophical Writings* (London, U.K.: Thomas Nelson and Sons, 1996), p. 3.