



The Left Atrium

The doctor and the zebra

One hundred days: my unexpected journey from doctor to patient

David Biro

Pantheon, New York; 2000

289 pp. ISBN 0-375-40715-4 \$35.00



An autopathography is a memoir of illness, an account of how it feels to be on the receiving end of medical care. Perhaps the most famous specimen of the genre is Norman Cousins's *Anatomy of an Illness*, oft cited as the story of how a patient bucked authority to laugh himself back to health. Doctor-written autopathographies have enjoyed a special status for centuries. In the 1600s, for example, Thomas Sydenham wrote about his gout with such eloquence that his description is now a classic. Some physicians have incorporated their own case histories into research publications anonymously. Others have proudly proclaimed their experiences, advancing the cause of neglected diseases through professional identification. Several editors have published collections of medical autopathographies: Albert Grotjahn in 1929, Max Pinner and Benjamin F. Miller in 1952, Raymond Greene in 1971, and Harvey M. Mandell and Howard M. Spiro in 1987. Clinicians are fascinated by the genre — perhaps because they are intrigued, if not intimidated, by role reversal, a frustrating if enlightening movement from active to passive. *One Hundred Days* is an entertaining addition to this tradition.

In 1996, at the age of 31, David Biro, a Jewish New Yorker, was only weeks away from his final examinations in dermatology. Married, athletic, Italophile and writerly (he had a novel in progress), he was happily set to share office and career with his dermatologist father. A vague clouding of his vision was quickly diagnosed as retinal vein thrombosis. But what caused it? After repeated testing with conflicting re-

sults, he is found to have a true medical “zebra,” the rare blood condition of paroxysmal nocturnal hemoglobinuria (PNH). The young skin specialist and his family fret over the uncertainty of diagnosis in the unfamiliar territory of hematology. Once they have a diagnosis, knowing what — if anything — to do in terms of treatment is even more challenging.

Biro's physicians at the Sloan Kettering Memorial Hospital are real hematologists, and he uses their real names. But their “personalities” spring entirely from the reactions they inspire in their patient, and those reactions vary from day to day. Biro contrasts shy but determined Hugo Castro-Malaspina, a marrow transplant expert, with the warm but cautious Lucio Luzzatto, an expert on PNH recently arrived from Biro's beloved Italy. Biro adores Luzzatto and wants to stick with him; but Castro recommends a transplant, and Biro hears “cure.” Impatient, and finding a suitable donor in his youngest sister, he opts for the transplant. It is clear, however, that his decision is conditioned by personality and transference as much as by the diagnosis. The rest of the book is devoted to the arduous consequences of Biro's choice.

The preparations are frantic and comic, especially the process of banking sperm. The pain involved in radiation and chemotherapy and the six-week imprisonment in a small hospital room are described in graphic detail. Biro suffers all the complications: exquisitely tender

radiation dermatitis that causes his scrotum to slough completely, severe mucositis of mouth and esophagus, hepatitis, unexplained fever, drug-induced delirium, weakness, weight loss and fears of impotence. Biro's parents, sisters and friends leap into action to provide round-the-clock support. His independent wife, Daniella, is put off by the intrusion as much as she is reliant on it to compensate for her necessary absences. While Biro's body falls apart under the onslaught of cytotoxic drugs and narcotic analgesics, his family and marriage are subjected to equally destructive forces. Yet all — body, family, and marriage — emerge intact, though altered by the experience.

Biro knows he is not the first doctor to learn that being a patient is full of unpleasant surprises. He portrays himself with candour: sheltered, naïve, privileged and perhaps even spoiled. By the end of the treatment, he appears less changed than his wife and parents by the intimations of mortality; however, he has more self-knowledge and greater understanding of how the ravages of illness can extend beyond the patient's body. Biro is conscious of and grateful for the ease with

which he obtains specialist consultations, but he glosses over the quick arrangements made for insurance coverage through inside contacts — an advantage that might be envied by less privileged readers in the US. His tale is interspersed with lucid explanations of bone marrow function and T-cell depleted transplantation, useful to anyone facing this procedure. But these explanations interrupt the personal tale of unusual family dynamics, which is, for me, much more compelling.

The strength of this book lies in Biro's superb portrayal of unique people and of the effect that one man's ill-



Fred Sebastian

ness had on them all. How many clinicians move into practice with their fathers? How many have mothers who would make daily house calls to rout out germs? Which of them would welcome the displacement of their spouse and colleagues by family, or expect this displacement to be tolerated for weeks on end? Excerpts from the diaries of both anxious parents reveal their fears and feelings of guilt. The diaries also

reveal that this book, planned even before the donor cells were harvested, reverts family confidence in a gifted son.

One Hundred Days, like Napoleon's famous comeback, does not end in closure but in ignominious transfer to St. Helena, an indeterminate but not intolerable island state floating between health and disease — a state we always occupy, although usually unaware. The irony is that Biro's continued fragility two years

post-transplant is no longer a product of PNH alone, but also of his treatment decision. What might have happened if his personality had allowed him to follow Luzzatto's recommendations and do nothing? We are led to believe he would be dead. But we will never know.

Jacalyn Duffin

Hematologist and medical historian
Queen's University, Kingston, Ont.

Lifeworks

Man of the mill

Born in the year of Confederation, Dr. Robert Tait McKenzie left his mark on Canadian medical history not only as a pioneer in preventive and rehabilitative medicine but also as a highly skilled sculptor who celebrated the human form and human effort through his art. This life's work is hon-

oured at his little-known summer home, the Mill of Kintail, near his birthplace in Almonte, Ont., where he and his wife, a poet and pianist, worked and entertained from 1930 until his death in 1938. Situated on a 167-acre site some 50 km west of Ottawa, the picturesque mill remains as McKenzie left it. His studio houses

over 70 plaster originals as well as original bronzes of his sculptures, friezes and medallions. These works include *The Joy of Effort*, which was used as a model for Olympic medals in 1912. His rawly seductive *Masks of Facial Expression* (1931-32) record stages of physical exertion. *Onslaught* (1911) depicts a rugby scrimmage and is now the Ivy League football trophy. Dominating the studio is a plaster cast of the centerpiece of his impressive Scottish American War Memorial; the finished work is in Edinburgh.

Despite the significance of these works, they are endangered by underfunding. Much-needed repairs to the mill have been delayed since 1996, when provincial funding was pulled. The Mississippi Valley Conservation Authority (www.mvc.on.ca),



The design of *The Joy of Effort* (1912, 269 cm in diameter) is deemed to be one of McKenzie's most accomplished in the placement of the runners and degree of relief. The artist modelled it after a school of porpoises he once saw leaping through the water; his athletes have the same cresting movements.



Among McKenzie's seven larger outdoor monuments scattered across the globe is *Memorial to Jane A. Delano and 296 Nurses Who Died in World War I* (1933), located at the Red Cross headquarters in Washington, DC.

custodian of the property since it was opened to the public in 1972, is hoping to build a trust fund to maintain the site and increase national awareness of McKenzie's legacy.

McKenzie's ideas are still recognized as innovative by sport and health organizations across North America. After graduating from the faculty of medicine at McGill, where he excelled in gymnastics more than in academics, he became its first-ever medical director of physical training in 1894. McKenzie held the revolutionary belief that exercise was an in-