Introduction: *Not* the Draaisma syndrome

Sometimes memories don't take on meaning until years later. As a college student, I used to work weekends in an old people's home. One of my responsibilities was the bread cart: towards the end of the afternoon I did the rounds of the rooms, together with a geriatric assistant, delivering the day's cold meal. If someone was visually handicapped or had trouble walking, we also laid the table. One afternoon, as we were rummaging in the cupboard of one of the residents for china and cutlery, the lady suddenly announced that there was a little man outside in the garden. A little man? We followed her gaze. There was nothing unusual in the garden. But she insisted: 'There's a little man there.' I looked to see if there was anything she could have mistaken for a man. I saw a lamp-post among the bushes, about a metre high, with a cap that looked vaguely like a hat. 'Do you mean that lamp over there?' 'Of course not! I can see it's a lamp!' We assured her that neither of us saw anyone outside. As the assistant pushed the woman's chair closer to the table, she rolled her eyes and tapped her forehead with one finger. At the time, that seemed to me a satisfactory explanation. We called out a cheery 'Enjoy your meal!' and continued on our way.

It was some twenty years later that I read about quite a rare syndrome that affects mainly older people with failing eyesight. They begin

seeing things – usually images of people, often miniaturized. They appear just as twilight falls and it starts to go quiet. The phenomenon, which is quite harmless, is called Bonnet syndrome. It is named after Charles Bonnet, a Swiss naturalist and philosopher, who in 1760 was the first to describe these images. Bonnet hadn't seen them himself; he had been told about them by his grandfather, who began seeing images of people when he was almost 90, after several failed cataract operations.

I had met someone with Bonnet syndrome and hadn't noticed anything unusual. I realized then how easy it is *not* to discover something. And even if I had, it would have been a 'rediscovery'.

Why is it that Bonnet 'saw' it and I didn't? One obvious difference, though not the only one, is that he took his grandfather seriously. That in itself was no mean accomplishment, for the old man insisted that he saw not only people, but also fountains, carriages some 30 feet high, a rotating wheel floating through the air. Instead of concluding that his grandfather was failing mentally, Bonnet accepted the authenticity of the images and considered possible explanations. He went on to describe in one of his books a neurological disorder that can cause visual sensations without affecting one's judgement. In the following chapter, we will see how in 1936 that disorder became Bonnet syndrome, and how subsequent generations of psychiatrists and neurologists have attempted to explain those images.

But what if there had never been a Bonnet, and I had taken the woman with her 'little man in the garden' just as seriously as Bonnet took his grandfather? Would there now be a 'Draaisma syndrome'? The answer is an unequivocal 'no'. If I've learned one thing from this study of twelve name-givers active in the field of brain science, it is that what happens *after* a discovery is more important than the discovery itself.

To focus on just one element in those further developments: the discovery must be registered. In this respect, each era has its own conventions. Where Bonnet described his observations in a book,

today's neurologists and psychiatrists communicate via specialist journals, and there are specific criteria for the research and the presentation of findings. Today, a simple description of a single case carries very little weight. An aspiring name-giver must collect a considerable number of similar cases (100 is better than 50) and provide the particulars of each one, such as age, sex, vision, medication and educational level. He must also come up with an explanation for the phenomenon, preferably one borne out by experiments that make it clear which factors influence the occurrence of such images. Then the beginnings of a consensus must be arrived at within the scientific community as to whether the phenomenon in question is indeed one which cannot be classified within any existing psychiatric or neurological syndrome. After that, an authoritative colleague (or a committee) must propose that the name of the author be attached to the disorder. And only when the scientific community actually begins to refer to that name can we say that a new 'discoverer' has been added to the annals of brain science. Clearly, all this lies far beyond the possibilities of a college student with a part-time job. In fact, even Bonnet wouldn't have stood a chance today. 'Your grandfather, you say? And what exactly did he see?'

Linguistically speaking, 'Bonnet syndrome' is an eponym: a proper noun turned common noun. The 'donor' invariably drops his or her first name, while in the case of the best-known eponyms – Alzheimer, Parkinson, Korsakoff and Asperger – even the designation 'disease' or 'syndrome' has become superfluous. And not only do their first names disappear, but after a while the rest also fades away, including recollections of their lives and the circumstances surrounding their discoveries. For twelve of these eponymists I have tried to serve as a 'resurrectionist' – not in the grim sense attached to the term in the days of James Parkinson, but as a historian striving to bring to life their thoughts and ambitions, their struggles and hopes, in short, turning names into people again. It was a privilege to give the eponymists the attention they deserve, by making each one the subject of a chapter.

Why eponyms? And why these eponyms? There are valid reasons for choosing them, but valid reasons are not always the original motive. What initially drove me was curiosity, pure and simple. *Who were these people?* What was the drive behind their discoveries? Later, as I began to explore those lives long past, other questions presented themselves. Who saw to it that their names were immortalized? Is the condition we call the Tourette syndrome the same disorder that Gilles de la Tourette described all those years ago? What was Parkinson's disease before Parkinson? What form did Alzheimer's disease take before the neuropathologist Alzheimer revealed to his colleagues what he had found in the brain of Auguste D? Why was the disorder described in 1944 by the Viennese paediatrician Asperger not discovered earlier, since everything indicates that there have always been individuals with the behavioural abnormalities which are today grouped together as 'Asperger'? How is it possible that Asperger himself was not discovered until 1981, a year after his death, and his original article went almost unnoticed?

The valid reasons referred to above have to do with the key position of eponyms within the scientific enterprise. They are among the processes which regulate scientific prestige and recognition. According to the sociologist of science, Robert Merton, it is through eponyms that 'scientists leave behind their indelible signature in history; their names enter into all the scientific languages in the world'.[1] High on the firmament we find eponyms like Newtonian physics, Euclidian geometry and the Copernican system. The echelon which follows consists of a long series of 'fathers' of sciences, disciplines or specializations: Bernoulli, 'father of mathematical physics'; Wundt, 'father of experimental psychology'; Hughlings Jackson, 'father of British neurology'. Many of these 'fathers' (Merton predates the first 'mothers') live on in such 'ordinary' eponyms as the theorem of Bernoulli and Jackson's epilepsy. Literally everything that exists, in whatever form,

[1] R. K. Merton, *The Sociology of Science* (Chicago, 1973), p. 298.

can be named after its discoverer: propositions, plants, laws, hypotheses, distributions, instruments, tests, narrows, comets, craters on distant planets, scales, effects, classifications, proofs and visual illusions. Even mistakes or conjectures can be crowned with an eponym: it appears that the 'conjecture of Poincaré' has recently been demonstrated (even though the mathematician in question has vanished without a trace). A less desirable form of immortality is the eponym that designates something which upon further consideration does not exist, like the 'canals of Schiaparelli', which the Milanese astronomer Giovanni Schiaparelli observed on Mars in 1877. Outside the scientific world, immortality is decidedly short-lived: the name of James Watt does not spring to mind every time we change a light bulb, nor do we think of John Loudon McAdam whenever we turn onto a highway.

Down through the ages, physicians have honoured one another with literally thousands of eponyms. There are eponyms for parts of the body, operations, symptoms, reflexes, diseases, syndromes, instruments, tests and reactions.[2] An extensive list can be found at www.whonamedit.com. At the moment of writing, the site contains 3,225 entries. It is in English, so that it may be slightly skewed in favour of Anglo-Saxon medical science, but its sheer size enables us to draw a number of interesting conclusions. Physicians active during the last quarter of the nineteenth century or the first quarter of the twentieth century had the best chances of being so honoured. After that, medical research became increasingly a matter of teamwork, and individuals were less likely to be immortalized in an eponym. Today, eponyms continue to be bestowed (relatively more often in clinical genetics), but there is a clear preference for descriptive designations

[2] A selection of over fifty neurological eponyms appear in P. J. Koehler, G. W. Bruyn and J. M. S. Pearce (eds.), *Neurological Eponyms* (Oxford, 2000). For my chapters on Broca, Korsakoff and Jackson, I drew upon the relevant contributions in that collection. Other useful sources were D. Arenz, *Eponyme und Syndrome in der Psychiatrie* (Cologne, 2001), and P. Beighton and G. Beighton, *The Person Behind the Syndrome* (Berlin, 1997).

or abbreviations, as in AIDS, ADHD or ALS (previously known as 'Charcot's disease').

Of the eponyms which appear on www.whonamedit.com, the highest number come from the United States (819), followed by Germany (636), France (428), the United Kingdom (340) and Austria (155). The Netherlands (46) just misses the top ten, coming after Sweden (52) and Denmark (48). Where the date of attribution is concerned, there are considerable differences between the various nationalities. Of the Americans, some 39 per cent were born after 1900, whereas only one of the 25 Czech eponymists was born in the twentieth century, a reflection of the fact that the Czech Republic's heyday as a centre of medical research lies in the past. Austria's high ranking is likewise due mainly to its illustrious past: fewer than 13 per cent of its eponymists were born in the twentieth century. Germany, France and the United Kingdom have traditionally been among the medical superpowers, and that holds true even today; they also have a high proportion of relatively young eponymists.

The 340 UK eponyms span over four centuries of medical history. The seventeenth century is represented by such luminaries as Willis and Sydenham. Thomas Willis, an Oxford anatomist, first described the circle of arteries at the base of the brain, and was also the name-giver of Willis' disease, an obsolete term for diabetes mellitus. Thomas Sydenham, 'the father of English medicine', identified a disease of the nervous system which causes involuntary movements of trunk, arms and legs that resemble a kind of jerky dance: Sydenham's chorea. Some nineteenth-century eponyms that were once well-known have disappeared or been rechristened. William Smellie, a Scottish obstetrician, was known for the Smellie manoeuvre, a manipulation during breech delivery in which the after-coming head is delivered while the child rests on the physician's forearm. This procedure now goes by various names, each country favouring its local inventor. Most eponyms, in the United Kingdom as elsewhere, have their origin in the nineteenth century. That was the era of James Parkinson and John

Hughlings Jackson, whose eponymic contributions will be dealt with in separate chapters. But there are many more. Sir Charles Bell found his name attached to a nerve, a paralysis and a type of spasm. His main claim to fame is probably the Bell-Magendie law, stating that the anterior spinal nerve roots contain motor fibres and the posterior roots sensory fibres. Pathologist Thomas Hodgkin lives on in the name of a particular type of cancer which attacks lymphatic tissue.

As befits a British list, it features more than a few eccentricities. The 'albatross reaction', described in 1967, refers to patients who after a gastrectomy start pursuing their surgeon, like the albatross that followed the ship in Coleridge's 'The Rime of the Ancient Mariner'. A more recent work of literature inspired the identification of the 'Alice in Wonderland syndrome', first described in 1955 by a psychiatrist called John Todd. This syndrome involves distortions of time, space and body shape which are sometimes experienced as a consequence of migraine headaches. Lewis Carroll himself is known to have suffered from migraines.

There are almost a dozen women among the British eponymists, such as Yvonne Barr, whose name is associated with the Epstein-Barr virus. They include many paediatricians and geneticists. Of the 3,225 entries on persons listed at www.whonamedit.com, only 117 are women eponymists. A number of factors seem to have conspired against them, since by the time the study of medicine was opened to women and they began to make their contribution, the great wave of naming was already over.

The vast majority of medical eponyms are intended to honour priority: the designer of a new operation, the inventor of an instrument, the first person to describe a part of the body, the discoverer of a disease. When that priority is challenged, bitter conflicts can result, giving rise to issues that are of greater interest than priority alone. What exactly is a 'discovery'? Which factors determine whether something is a 'discovery' in the eyes of the scientific community? Can we call someone a 'discoverer' when he himself had no clear

understanding of what it was he discovered, as seems to have overcome the man who first identified the area of Broca? Questions such as these are at the heart of the scientific enterprise. Eponyms are at once accolade and arena. They are the site of manoeuvre and manipulation, where power and authority are at issue, where conflicts over what constitutes a scientific proof are settled, and where decisions are taken on matters of classification and categorization. As the historian of neurology, Anne Harrington, once remarked, 'the modern-day scientist, interested above all in how the human mind and brain "really" work, should also give some thought to the question of how science "really" works'.[3] Eponyms mark the spot where these two questions intersect.

But why *these* eponyms in particular? For the most part, I was guided by my own curiosity, although the end result is not entirely arbitrary. There was a striving to make the selections representative, in a historical, geographical and disciplinary sense. Gilles de la Tourette, Capgras and Clérambault are all representative of French psychiatry, with its focus on patient demonstrations. Capgras described a syndrome whereby the patient is under the misapprehension that his loved ones (wife, children and friends) have been secretly replaced by *doppelgängers*. In Clérambault's syndrome, the patient (usually a woman) is convinced that someone is in love with her. These three – Gilles de la Tourette, Clérambault and Capgras – all carried out their investigations within the psychiatric institutions to which they were attached. Capgras and Clérambault published their results in the form of clinical lessons, a method of communication which was then held in high esteem in France. Alzheimer and Brodmann (who drew up a map of the human brain) were both a product of the German tradition of neuropathological research. Their studies were carried out in a laboratory, and their most important instrument was the microscope. Alzheimer was an institutional physician who did his rounds with

[3] A. Harrington, *Medicine, Mind, and the Double Brain* (Princeton NJ, 1987), p. 286.

great dedication, but believed that his greatest service to his patients was rendered after their brains became available for microscopic examination.

Representativity with respect to disciplines is a far more difficult matter. Throughout history, many diseases, syndromes, disorders and conditions have regularly changed position with respect to what we now call 'neurology' and 'psychiatry', which up until the late nineteenth century were regarded as a single field of science. James Parkinson, a GP in one of the poorest neighbourhoods of London, had no inkling as to the cause of the 'shaking palsy' which he described in 1817, although he suspected that something had gone awry in the brains of his patients. But Charcot, the Paris neurologist who in 1876 named the disease after Parkinson, believed that it might well be related to psychological factors, such as a violent shock or severe emotional stress. As a result, Parkinson's disease underwent a shift in the direction of psychiatry. Today, the degeneration of a small area of the brain that produces the neurotransmitter dopamine is seen as the cause of Parkinson's, which brings the disease back into the field of neurology. These changes in perspective are the rule rather than the exception. The syndrome of Gilles de la Tourette has never ceased hopping back and forth between neurology and psychiatry. While the syndrome of Capgras had long ago been defined in psychoanalytical terms, in the last twenty years it has shifted in the direction of neurology. In the case of the Asperger syndrome, a disturbance which is part of the autism spectrum, the role played by neurological factors is still unclear.

As noted above, the decision to study eponyms almost automatically placed the centre of gravity of the selection in the nineteenth century and the consequences of this fact are reflected in the portraits in *Disturbances of the Mind*. Despite the differences, what the eponymists have in common is the fact that they all made use of case studies. Together, they are representative of a scientific style which disappeared half a century ago. In case histories, the elements of care and

treatment, observation and research are still closely intertwined. Parkinson writes with compassion about a patient who had his servant run ten metres ahead, so that the man could catch him when his slow shuffle turned into a headlong dash. That same compassion resonates in Alzheimer's description of the state of desolate confusion in which Auguste found herself, and in Korsakoff's account of the total lack of imprinting skills among his patients. In Hans Asperger's 1944 case histories of his 'difficult children', the experience of the patient echoes throughout each account. If in these twelve portraits I have succeeded in transforming names into people of flesh and blood, then it is because their case histories are about people of flesh and blood.