Genetic Counselling in Belgium: The Centre for Human Genetics at the University of Leuven, 1960–1990

Joris Vandendriessche

Abstract This chapter traces the history of the Center for Human Genetics (CHG)—the first centre of this kind in Belgium—at the University of Leuven from the 1960s to the 1990s. In 1960, a laboratory for diagnostic chromosomal research was set up by the physician and geneticist Herman Van den Berghe. In 1966, this laboratory was turned into the Center for Human Genetics (CHG), which combined a service of genetic counselling with genetic research. The paper discusses the evolution of the Leuven CHG in relation to developments within the Faculty of Medicine and the University of Leuven, to government policies on genetics and to wider social debates. The CHG's expansion in the 1970s, 1980s and 1990s was paralleled by governmental attention to the field of human genetics and the life sciences. State support was allocated to eight genetic centres, which—following the Leuven model—were integrated into the Belgian academic hospitals, resulting in a decentralised model. This system of financing contributed, it will be shown, to the multidisciplinary nature of genetic research and counselling in Belgium. The paper also pays attention to contemporary ethical debates about medical technologies, of which genetic diagnoses were part. While these debates were conducted nationwide, they were particularly present at the University of Leuven, as the institution struggled to reconcile its Catholic heritage with its modern research ambitions.

Keywords History of medicine • Genetic counselling • Academic medicine • Medical ethics • Science policy • Belgium

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J. Vandendriessche (✉)
Cultural History since 1750 Research Group, University of Leuven, Blijde Inkomststraat 21, PB 3307, 3000, Leuven, Belgium
e-mail: joris.vandendriessche@kuleuven.be

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1 Introduction

Genetic counselling in Belgium is thoroughly integrated in the country's academic hospitals. The state support for genetic clinics and research that developed since the 1970s was allocated to eight genetic centres, located at the Belgian universities. They received governmental subsidies to conduct genetic tests—a measure that was coupled to strict quality control, the need to conduct scientific research, to offer psychological guidance to patients and to inform the public about the implications of genetic testing and research. Unlike in other countries, where 'genetic counsellors' developed as a professional medical subgroup, genetic counselling in Belgium is performed by physicians, often paediatricians. From the start, and increasingly with the availability of new genetic tests, they collaborated closely with other (medical) specialists, such as gynaecologists, psychiatrists, psychiatric nurses, psychologists, remedial educationalists, etc. As a result, Belgian genetic counselling has gained a strong multidisciplinary outlook—a second particular feature—which has reinforced its integration within academic health centres.

The recent history of genetics in Belgium remains to be written.[1] This chapter is intended as a first step in unravelling the field's historical trajectory by focusing on one centre—the *Centre for Human Genetics* (CHG) at the University of Leuven, which played a central role in the development of the integrated and multidisciplinary Belgian model. In 2016, the Leuven CHG celebrated its fiftieth anniversary with lectures from international researchers, a formal academic session, a conference on 'Genetics and Society', a series of postgraduate lectures and a visit of the Belgian queen.[2] If today around 350 people work at the CHG, in particular in its major research and diagnostic laboratories, only a handful of members made up the staff 50 years earlier, as a *Laboratory of Cytogenetics* was established as a separate unit within the *Department of Human Biology* in 1966 and a separate clinical service was started in the Leuven academic hospital. Its history, however, may be traced back even further. In 1960 already, a one-man laboratory, run by Herman Van den Berghe, provided diagnostic chromosomal research to patients transferred from other clinical services.

The focus of this chapter is not so much on the considerable expansion of the scientific research and genetic tests performed at the *Centre for Human Genetics* in Leuven, which have been treated in several retrospective brochures.[3] My aim is rather to place the centre in a wider historical context and discuss its trajectory in

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[1] While the post-WW II history of genetics in Belgium has been hardly studied, some work has been done on genetics in the interwar years: De Bont, 2007; De Raes, 1989.

[2] For an overview of the activities organised to celebrate the CHG's fiftieth anniversary and the current organization of the centre: http://gbiomed.kuleuven.be/apps/cme/.

[3] Three retrospective brochures have been published by the Leuven *Centre for Human Genetics* which allow a look into the centre's developing research activities. The first was published in 1987, when the CHG moved to the new medical campus of Gasthuisberg; the second in 1998, when Herman Van den Berghe retired as the centre's director; and the third in 2016, when the CHG celebrated its fiftieth anniversary.

relation to developments within the Faculty of Medicine and the University of Leuven and more generally to government policies on genetics and to wider social debates.[4] In this light, the embeddedness of the CHG in a Catholic academic institution has been essential. Particularly since the (late) nineteenth century, the University of Leuven emphasised its position as one of the major Catholic academic centres worldwide. This also meant that the ethical questions raised by genetic testing and research were answered in a particular setting, even though the influence of the Catholic Church over the University—in a secularising society—has equally been greatly diminished since the 1960s.[5] To open up this history, several interviews with (former) members of the CHG and with colleagues from other clinical services were conducted.[6] These have been combined with articles from the university's journal and from the Belgian general press.

2 The Politics of Genetic Research

The first support for genetics in Leuven after the Second World War was part of the University's programme of cancer research. Gerard Van der Schueren (1908–1978), originally a Professor of Anatomy who had become head of the *Radiotherapy Service* in 1952, followed the international research on the relation between cancer and heredity in the 1950s and 1960s closely. For his private archive, he cut out an article from *Time Magazine*, which reported of President Kennedy's support for researchers of mental retardation.[7] Another article he collected, now from a scientific journal, the *Belgian Review of Experimental Pathology*, was authored by Leonell Strong, who had presented his hereditary theory on cancer at a conference in Brussels, funded by Belgium's National Cancer Foundation.[8] While Van der Schueren himself had little time for research—he was also the director of the academic hospitals in those days—he seems to have realised the potential of genetics for cancer research and supported two young physicians, Herman Van den Berghe and Herman Verresen, who were interested in the subject. With them, he published several papers to promote genetics in Belgium. In of these papers—titled 'the promising morphological branch of

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[4] The research for this chapter is part of a larger book project on the history of the Leuven academic hospitals, which will place the evolution of these hospitals since the 1920s within a wider social and cultural context.

[5] For a recent history of the University of Leuven: Tollebeek and Nys, 2006.

[6] These interviews were conducted together with Liesbet Nys in the course of 2015 and 2016. Among the interviewees were Herman Van den Berghe, Bart De Strooper, Eric Legius, Gerry Kiebooms, André Van Assche, Paul Schotsmans, Bassem Hassan, Peter Marynen, Vanessa Morais, Annemarieke Sierksma and Iryna Voytyuk. In 2007, Peter Harper also conducted an interview with Herman Van den Berghe which is publicly available on the website of the Genetics and Medicine Historical Network: www.genmedhist.org/interviews.

[7] University Archive of Leuven [from here on: UAL], Archive of Gerard Van der Schueren [from here on: AVdS], N. 159, clipping: 'Chromosomes & the Mind', 1962.

[8] UAL, AVdS, N. 159, clipping: Strong, 'Une théorie génétique', 1949.

cytogenetics'—they explained the recent advances in the research on human chromosomes and called for clinical research within paediatrics (to trace hereditary disorders) and oncology (to study the effects of radiation on tumours).[9] Both topics would become central to genetic research in Leuven.

While Herman Verresen would develop his medical career at the university's campus of Kortrijk from the late 1960s, Herman Van den Berghe became the key figure in the development of genetics in Leuven. Born in Geraardsbergen in 1933, Van den Berghe obtained his medical degree at the University of Leuven in 1958. During the 1950s, the most talented students were often recruited to work voluntarily in one of the laboratories at the Faculty of Medicine. Van den Berghe was also encouraged to assist the staff at the *Vesalius* and *Rega Institutes*, where he learned the techniques of tissue culture and virology (e.g. titrating viruses). He also worked voluntarily at the Cancer Institute in Amsterdam, assisting in research on the role of hormones in breast cancer by conducting experiments on mice. As scientific work on human chromosomes seeped through into the Leuven medical world, Van den Berghe familiarised himself with chromosomal analysis and set up a small laboratory in the basement of the Vesalius Institute.

At the Faculty of Medicine, such new research laboratories were increasingly encouraged. A new generation of Flemish (Dutch-speaking) faculty members, including the internist Jozuë Vandenbroucke (1914–1987) and the microbiologist Pieter De Somer (1917–1985), who had founded the *Rega Institute* in 1954, supported the development of new subdisciplines. For Vandenbroucke, subspecialisation formed a means to strengthen the interplay between clinical work and research in the medical sciences; De Somer, who had a background in virology, called for more fundamental research at the Faculty of Medicine. Both agreed that the existing structures within the faculty were unfit to enable innovative research. They advocated the creation of 'departments', through which the research funds of the Faculty of Medicine would be better divided.[10] Both also merged this agenda of reform with the ambition of improving the position of Dutch-speaking physicians in the Leuven research laboratories, which hitherto had been dominated by their French-speaking colleagues. Linguistic tensions would eventually lead to the splitting-up of the University of Leuven in 1968—a major event in Belgium's political history and one in which the Leuven physicians played a key role.[11] De Somer became the first rector of the now Dutch-speaking university. The French-speaking physicians moved to the newly built hospital complex *Saint-Luc* in Sint-Lambrechts-Woluwe, near Brussels, where an independent service of genetic counselling for French-speaking patients would later be developed. Their gradual departure from the buildings on the medical campus in Leuven's city centre

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[9] UAL, AVdS, N. 159, draft paper: Van der Schueren, Gerard, Van den Berghe, Herman and Verresen, Herman, 'De cytogenetica: een veelbelovende morfologische tak'.

[10] Nys 2016, 94–100.

[11] Vandendriessche and Nys 2017.

provided Van den Berghe with additional space to expand the Dutch-speaking CHG.

Parallel to the more positive climate for specialised research in the Faculty of Medicine, the clinical function of chromosomal research within the Leuven academic hospitals became clear. By 1960, Van den Berghe became regularly contacted to assist in the diagnosis of disorders related to the sex chromosomes from the service of endocrinology and gynaecology. Other types of patients that were referred to him from early on were those treated for myeloid leukaemia by the Leuven haematologists. Moreover, also outside of Leuven, the laboratory's diagnostic work became known. Blood samples from patients in regional hospitals were sent to Van den Berghe for analysis. This clinical potential made that in 1966, when the departmental structure was finally introduced in the Faculty of Medicine, Van den Berghe's *Laboratory of Cytogenetics* was not only integrated in the *Department of Human Biology* as a research laboratory. Simultaneously, an independent clinical service was set up within the hospital, which would be expanded by Jean-Pierre Frijns. Both components together formed the *Centre for Human Genetics* (CHG).

The further expansion of the CHG followed swiftly as the centre sought affiliation with geneticists on the international level. Van den Berghe himself had conducted an internship at the *Galton Laboratory* in London with Lionel Penrose (1898–1972) in 1962 and received further training in genetics in Paris and Seattle. In the 1970s, several staff members, including Jean-Jacques Cassiman, Fred Van Leuven, Guido David and Peter Marynen went abroad for research stays (e.g. to Stanford University), bringing back expertise in different types of genetic research to Leuven. This allowed the research activities of the CHG to expand rapidly in different directions (e.g. cancer research, somatic cell genetics and forensic genetics). Robert Vlietinck developed a research group in population genetics, which cooperated with the University of Ghent in studying identical twins. It was 'a golden speedway for genetic research', in Vlietincks' words.[12] Since the middle of the 1960s, a twin register had been kept in Ghent, which was later continued by the Leuven CHG. In the genetic clinic, much research was conducted on X-linked mental retardation by Frijns and later Eric Legius, for which they cooperated with numerous institutions for the mentally disabled, examining thousands of patients over the years. On the basis of these data, they were able to identify and describe several new chromosomal syndromes.

The expansion of these research activities did not only increase the centre's academic staff. From its early years, laboratory assistants—mostly women—made up the largest group of personnel. This gender balance between the technical and academic personnel would only gradually alter in the 1980s. The psychologist Gerry Kiebooms became the first woman to be appointed officially in the centre's academic staff in 1987. Most of this personnel was paid with research funding from the Faculty of Medicine. In addition, the CHG also became a successful candidate in different competitive research programmes, both on the level of the university

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[12] 'Tweelingenonderzoek', 1987.

and on the national level (e.g. the National Cancer Funds). Even more important was the Belgian Fund for Medical Research, which had been established in 1957 as part of the country's health politics and which was financed by the Ministry of Public Health. Increasingly, the existing mix of public and private (industrial) funding for science became complemented with larger topical research programmes from the state—it meant the hesitant introduction of 'Big Science' in Belgium. Medical research was among the strategic areas, in which the state ambitioned to take a leading role. It formed an important stimulus for the CHG's expansion.[13]

Shifts in Belgium's science policy since the late 1980s further impacted the expansion of the CHG's research activities. The Belgian state reforms of 1988 transferred most of the decision-making on state support for science to the regional level (e.g. the Flemish government). Even though the mentioned Funds for Medical Research provided certain means, subsidies for scientific research still compared poorly with similar policies abroad. When new budgetary cuts were proposed in 1992, a national march was organised in Brussels, to which 10,000 researchers participated. The protest was organised by Research Focus, an organisation founded in 1986 that aimed to promote scientific research in Belgium. Two young medical researchers—Bart De Strooper, a post-doc at the CHG, and Patrick Callaerts—played a key role in the initiative, which was supported by the university board.[14] The 1992 march proved a turning point in Flemish science policy. More funds were now allocated to the Flanders Research Foundation, the regional successor of the National Science Foundation of which the Fund for Medical Research had been part. More attention was also paid to the support of biotechnological research, which became one of the strategic areas in which the Flemish government invested. In 1990, a first programme (VLAB) had been started to support research in the life sciences. In 1996, a much larger initiative was taken with the foundation of the VIB, a life sciences research institute, heavily funded by the Flemish government. Van den Berghe was one of the advocates of this new institute, which, it is important to stress here, did not develop as an independent organisation but was fully integrated into the universities.[15] The CHG became one of the two Leuven 'core departments' of the VIB.

The funding from the VIB marked a new phase in the development of the Leuven CHG. Government attention for the life sciences had stimulated researchers such as Bart De Strooper to shift their focus to diseases as Alzheimer and Parkinson, for which major research programmes were now set up. The bibliometric and result-based evaluation that came along with VIB-funding, some researchers have indicated, equally caused shifts in the centre's scientific culture. The merit-based system, it has been said, broke down the hierarchical structures and increased the autonomy of researchers. Another development that was reinforced by VIB was the

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[13] Halleux, 2015, 110–113.

[14] De Strooper and Callaerts, 1992. For a more elaborate discussion on the topic: Nys, 2016, 189–200.

[15] Ibid., 238–241.

internationalisation of the community of researchers at the CHG, which became an attractive work place for promising foreign researchers, some already with a high reputation. They, in turn, contributed to grant proposals on the European level, setting in motion a further process of expansion.

3 Integration into the Hospital

One of Van den Berghe's favourite sayings about the position of the CHG within the Leuven academic hospitals was *pour vivre heureux, vivons caché* [to live happily, live hidden]. It seems no coincidence that this phrase surfaced in many of the interviews with the centre's (former) members, not just as a recollection of Van den Berghe's style of leadership but also as a reflection of the particular nature of the genetic clinic. Unlike other clinical units, the CHG did not have its own hospital beds—an essential marker in hospital organisation. Neither did genetics constitute an essential part of the training of medical students. As many recalled afterwards, in its early years, the activities of the CHG were little known by other physicians in the hospital. Its original location, hidden in the basements of the *Vesalius Institute*, did not contribute to the centre's visibility either. The CHG would later expand to old buildings of the University's technical services in the De Croylaan. In the late 1980s, it moved to the research buildings 'O&N' on Gasthuisberg, the new medical campus outside the city centre.

While the CHG's 'hidden' position in the hospital was given multiple meanings by the interviewees, the argument of the centre's financial autonomy often recurred. The centralised hospital administration originally had little control over the budgets of each clinical service, giving these services considerable autonomy—it was the time of the 'far west' in the academic hospital, as some recalled. The genetic clinic indeed secured its own financing through different governmental channels. Since the late 1960s, a politics of subsidising genetic tests and research into hereditary diseases was launched. In 1968, a law was voted that recognised and supported centres that conducted diagnoses of phenylketonuria (PKU), a hereditary metabolic disorder. It was inspired by the fact that PKU 'entailed a serious mental retardation if it was not traced timely.'[16] Five years later, in 1973, a *High Council for Human Genetics* was founded which was to stimulate the development of genetics in medical and social ways. It was also to add to programmes of prevention and registration.[17] The director of the division 'social medicine' at the Ministry of Public Health became president of the council and Van den Berghe its vice president. Together with this council, an *Interfaculty Institute for Human Genetics* was set up through which additional governmental subsidies were divided to seven

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[16] 'Opsporing van fenylcetonurie', 1968.

[17] 'Hoge Raad voor de Antropogenetica', 1973.

(later eight) genetic centres, located at the Belgian universities.[18] Moreover, the different laboratory tests conducted at these recognised centres were reimbursed by Belgian social security.

The isolated position of the CHG within the Leuven hospitals, at the same time, has to be nuanced. Van den Berghe's saying was most of all applicable to the centre's early years. An evolution towards more collaboration between different clinical services, for example, by organising multidisciplinary consultations—an evolution not limited to the field of genetics—paralleled the growth of the CHG in the 1970s and 1980s. Jean-Pierre Frijns started joint prenatal consultations with Kamiel Vandenberghe (1940–1997), a member of the *Gynaecology and Obstetrics Service*, who became known for having introduced and spread ultrasound imaging in the hospital. Many couples with anxieties over hereditary defects, who had often already been informed by the CHG, found their way to these consultations. Techniques such as ultrasound and amniocentesis became more common—the latter practised at the *Gynaecology and Obstetrics Service*, but always in the presence of a laboratory assistant of the CHG, who transported the amniotic fluids to the laboratory for analysis. Other multidisciplinary consultations were set up in collaboration with paediatric neurologists and cardiologists, for example, on neuromuscular disorders and on specific hereditary diseases such as neurofibromatosis, on which Eric Legius was the centre's specialist.[19]

With the availability of new genetic tests since the 1980s, the patient potential of the CHG increased dramatically. More and more physicians were added to the staff of the genetic clinic (which today consists of eight full-time positions). Moreover, a network with ten regional hospitals was set up, the Leuven geneticists travelling to each of these hospitals once a month to organise consultations. By 1993, almost 5000 patients got into touch with the centre each year. Among them are older couples, who desired to have children and inquired after possible risks of pregnancies at a later age; patients of whom a family member carried a genetic defect and who sought to know whether or not they carried the gene as well; and, with the discovery of genes that increased the risk of breast cancer or heart disease, patients interested in all sorts of risk assessment. With these new tests, as Jean-Pierre Frijns explained in an interview, the practice of genetic counselling developed as well. The international guidelines of 'non-directiveness' in assisting patients' decision-making were stressed at the Leuven centre. Good counselling was needed, Frijns concluded, in order for 'our technology to be at the service to those who wish to make a decision.'[20]

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[18] In a budget report of 1973 of the Belgian senate, such an interfaculty institute is mentioned: http://www.senate.be/lexdocs/S0642/S06421172.pdf (Consulted on January 29, 2017), p. 16. A subsidy of 25.000 F was granted. On the website of the Antwerp Centre for Human Genetics, a brief history of the centre is included: http://www.uza.be/over-het-centrum-medische-genetica-cmg (consulted on January 19, 2016).

[19] For an overview of these consultations in the 1990s: Centrum voor Menselijke Erfelijkheid, 1998, 72.

[20] 'Klinische genetica', 1993.

The psychological effects of genetic testing on patients, from the possibility of taking them to the prospect of future illnesses, became itself also subject to research. In 1977, Gerry Kiebooms had joined the CHG and since the late 1980s developed a unit of 'psychosocial genetics' within the centre. Clinical work formed part of this. The availability of new genetic tests, for example, for Huntington's disease, Kiebooms recalls, generated a fear of possible suicides by those who would test positively, hence, the need for psychological guidance—a necessity for which cooperation was sought with patient organisations. In collaboration with the Leuven psychiatrists, a shared consultation was set up on this subject, informing families about the effects of such tests and counselling them also after the results were made available. Using questionnaires, here as well clinical work was coupled to research.

Belgian legislation on genetic counselling stressed this need for psychological guidance and correct information. In 1987, a Law on Genetic Centres was voted in the Belgian parliament, which expanded the older system of subsidies and established the criteria genetic centres had to meet to receive financing. Offering counselling to patients, allowing them to make informed decisions, and informing the public about the developments of genetic research were part of this. The combination of clinical service and medical research was also stressed: the different centres were to study whether or not abnormalities, both mental and physical, were hereditary or not, concerning the nature of these defects and all elements related to being a carrier of these hereditary features.[21] The law was realised by Wivina De Meester, a politician from the Christian People's Party who was State Secretary of Public Health between 1985 and 1988. De Meester knew Herman Van den Berghe well, who advised her in debates over abortion. When the Leuven CHG moved to the new campus of Gasthuisberg in 1987, the same year as the new legislation, a solemn academic session was organised during which De Meester explained her policy and suggested the need to invite certain high-risk groups for genetic screening in the future.[22]

After 1987, the CHG employed a more proactive strategy, investing more means and energy in 'genetic education' and in explaining its workings to the outside world. It regularly organised an open house, during which one could visit its laboratories on the sixth floor of the Gasthuisberg research building. Educational films, books and booklets were released in which questions of genetic effects were explained. Members of the centre, moreover, also increasingly appeared in the media. In debates about AIDS, fertility, paternity tests among other subjects, the CHG clearly fulfilled a public role. This more public presence of the centre also illustrates the increased social importance of genetics in recent years, of which the ethical boundaries have equally become subject of public debate.

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[21] See the text of the Law on Centres of Human Genetics of December 14, 1987: http://www.ejustice.just.fgov.be/cgi_loi/change_lg.pl?language=nl&la=N&cn=1987121432&table_name=wet.

[22] 'Grote belangstelling', 1987.

4 Ethical Debates

Such ethical discussions were by no means new. At the Faculty of Medicine, much attention had gone to medical ethics since the 1960s. It was a means of engaging with contemporary clerical views on matters of reproduction, which seemed at odds with modern medical techniques. In 1968, Pope Paulus VI (1897–1978) had condemned ‘artificial’ forms of birth control in his encyclical letter *Humanae Vitae*. Despite this condemnation, the prescribing of contraceptive pills was continued in the academic hospitals and defended by the Leuven physicians as means to prevent abortion. In 1975, a *Commission for Medical Ethics* was founded—the gynaecologist Marcel Renaer (1913–2006) became its first president—that was to formulate advice on ethically sensitive issues such as sterilisation and artificial insemination. The ambition, which was supported by the Belgian bishops, was to establish a responsible, yet modern, ‘Catholic’ position on these matters. The commission’s advisory role was later supplemented with the need for research in medical ethics and its inclusion in medical education. Following an American model, a *Centre for Bio-Ethics* was founded at the University of Leuven in 1986. Paul Schotsmans became the centre’s first director and the first full professor of medical ethics at the Faculty of Medicine—courses in medical ethics having previously been taught by philosophers.[23]

Many of these ethically sensitive issues were foremost a matter for the Leuven gynaecologists. One of these was abortion, which—until a Law on Abortion was voted in 1990—was considered a criminal offence under all circumstances, following Belgium’s penal code of 1867. In the 1970s and 1980s, Belgian women seeking an abortion hence travelled to the United Kingdom or the Netherlands, where legislation had been voted much earlier than in Belgium. The 1990 Law was voted in the Belgian parliament without the support of the Christian People’s Party and made abortion legal until 14 weeks of pregnancy if performed in a recognised abortion centre. Against the background of an ongoing public debate on such legislation in the 1980s, prenatal diagnoses and fertility treatments were topics that evoked considerable attention in Catholic academic circles.[24] As historian Liesbet Nys has recently shown, the introduction of in vitro fertilisation—the first Belgian test-tube baby was born in Leuven in 1983—caused a disagreement between the board of the Faculty of Medicine, who feared to offend the ecclesiastical authorities and the gynaecologists who had used the technique.[25] If not always in a direct way, the *Centre for Human Genetics* was nevertheless involved in these debates. The chromosomal analyses conducted in its laboratories, such as the examination of amniotic fluids since the early 1970s, it was rumoured by some, led to an increasing number of abortions, for which women often travelled abroad. In case of severe genetic defects, or when the mother’s health was under threat,

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[23] Nys 2016, 143–145, 209–211.

[24] Witte 1993.

[25] Nys 2016, 147–150.

abortion was practised in the Leuven academic hospitals, also before 1990. Some of these rumours, according to which the Belgian bishops were furious about certain ‘unethical’ practices in the CHG, reached Van den Berghe, who remembered gaining their trust after a meeting in which he explained the centre’s functioning.

From the late 1980s onwards, the CHG became itself more involved in these ethical debates. At different occasions, Van den Berghe emphasised the social challenges that arose from the availability of all sorts of new (prenatal) genetic tests, pleading for debate and public education on these matters.[26] Within the *Centre for Bio-Ethics* as well, the implications of genetic testing were increasingly investigated, certainly after the publication of another encyclical letter, *Donum Vitae*, in 1987. The new letter stipulated that prenatal diagnoses could only be conducted if they were oriented towards healing and with respect to the ‘integrity of the human foetus’. They were ‘in opposition to moral laws’ if they provoked abortions. In 1988, members of the University of Leuven’s leadership, including rector Roger Dillemans and Guido Maertens (1929–2002), who taught medical ethics at the university’s campus in Kortrijk, visited the Vatican as part of a delegation of Catholic universities to explain the medical procedures in their hospitals. While they did not succeed in altering the Church’s view on the topic—in particular the creation of surplus embryos was regarded highly problematic—no conviction by the Church followed either.[27]

In the early 1990s, shortly after the mentioned Law on Abortion, the activities of the CHG were nevertheless looked at with Argus’ eyes. In 1992, the papal nuncio, a diplomatic representative of the pope in Belgium, contacted the Leuven rector Dillemans after hearing rumours that genetic tests led to abortions, reminding him of the encyclical letter *Donum Vitae*. Dillemans assured the nuncio that no clear genetic advice was given, but only information, and that genetic counselling was done in ‘a warm, humane and non-directive fashion’ to make sure that the patients understood all aspects well. When asked for their opinion, Dillemans argued, the geneticists emphasised the respect for human life, including the life of the disabled. At the end of his letter, however, he added that ‘Unfortunately, the analysis made by people with this information [. . .] is no longer in line with this traditional Christian value that gives meaning to suffering and sacrifice’. With the secularisation of Belgian society came indeed a shift in morality, of which Catholics such as Dillemans were critical. With genetic testing, hereditary defects were easier to prevent, contributing to a society in which the Christian-inspired meaning of suffering was eroded. Those with such hereditary defects, it was feared, might be less cared for and understood. For this reason among others, Paul Schotsmans pleaded for an ‘ethical framework’ for genetic counselling.[28]

Schotsmans did not stand alone with these views. In the 1990s, questions of genetic testing featured prominently in ethical debates. This was, for example, the

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[26] Van den Berghe 1986.

[27] Maertens 1988.

[28] Schotsmans 1998.

case at the *Overlegplatform Christelijke Ethiek* [Platform for Christian Ethics], of which Maertens was president, and in the organisation's journal *Ethische Perspectieven* [Ethical Perspectives]. One of the most delicate issues was the matter of surplus embryos, created during in vitro fertilisation, and their possible use for experimental research. For Maertens, such use was out of the question (a view he had also defended during the meeting with Cardinal Ratzinger in Rome in 1988).[29] Van den Berghe, however, in a double dialogue with Maertens in the University's journal, which was picked up in the general press, had declared that such research for him was justified. The fabrication of human embryos for scientific research he too condemned fiercely.[30] Van den Berghe's statement caused a storm in the media, during which he, as the director of the CHG, epitomised the 'modern' genetic research and its far-reaching consequences. The public debate showed how, after the abortion debate, genetics moved more into the centre of the public debate on medical ethics. The new techniques of pre-implantation genetic diagnosis (PGD) in the 1990s, which allowed genetic testing of embryos prior to implantation, further fuelled these debates.

5 Conclusions

This brief survey has indicated some links between the development of the *Centre for Human Genetics* at the University of Leuven and wider shifts in government policy, clinical care and ethical debates in Belgium. While it does not allow drawing any definitive conclusions, it has rendered some insight into the particularity of genetic research and counselling in Belgium. Both on the level of science policy and public health, it has been argued, the Belgian—and later Flemish—government invested considerably in the life sciences and opted for a decentralised model, in which subsidised centres were integrated within the country's academic hospitals. New types of multidisciplinary consultations exemplified this ongoing process of integration. The embeddedness of genetic counselling in academic hospitals furthermore made that clinical service and scientific research were easily combined, a feature which has been regarded a major strength of this model. At the same time, this brief overview has made clear that the centre's growing public role—a function insisted upon by the Ministry of Public Health—paralleled ethical debates about medical technologies in a secularising society, of which genetic diagnoses were certainly part. While these debates were conducted nationwide, they were particularly present at the University of Leuven, as the institution struggled to reconcile its Catholic heritage with its modern research ambitions.

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[29] Maertens 1988.

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