

Anomalous children and eponymous fame.

**The discovery of the first ‘typus Amstelodamensis’ girls by the Dutch pediatrician
Cornelia de Lange (1871-1950) in the 1930s.**

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The fascination with children who show some sort of anomaly is prevailing throughout history. Theories and beliefs about the causes of these anomalies, however, varied during time. In early modern times a scientific approach started to push aside the explanation of divine wrath that had deformed these individuals, in favor of a curiosity about the variety in human body forms and anomalies. This transformation not only resulted in descriptions and examination of ‘monsters’ and in exhibitions of ‘freaks’ or ‘queers’¹, but as well in meticulous research into anomalies and its causes during the 18th and 19th century.² In particular children born with malformations attracted the attention. This article examines the process of the discovery of a specific group of such anomalous children. The first children were recognized as different because of specific phenotypical characteristics they had in common. Later these children were considered anomalous in a specific way. They came to form a separate entity, a syndrome.

In 1916 the Dresden medical assistant Winfried Brachmann published his findings on the case of a little boy, brought into hospital six days after his birth. The boy deceased, however, on day nineteen while refusing nourishment. He showed remarkable malformations and Brachmann indicated the most conspicuous anomaly as ‘Monodaktylie durch Ulnadefekt, mit Flughautbildung in den Ellenbeugen’. Furthermore, the child was very small and showed strong growth of hair. Also his facial characteristics were abnormal, in particular his receding forehead. At the time the combination of these characteristics in one child was never reported before in literature. As Brachmann concluded in his article, the tendency for variations or anomalies in this individual was unmistakable.³ Since Brachmann was called into military action in World War I, his research into the specific condition of the boy was interrupted and never taken up again, which made the description of this one boy his full evidence of these pediatric symptoms.⁴

In 1933, however, the Dutch pediatrician Cornelia de Lange, published an article based on her observations of two girls with anomalies in the French journal ‘Archives des Médecine’. Although De Lange was well aware that it was ‘presque impossible de découvrir [...] un type nouveau’, she could not identify any similar cases in a thorough literature search, which implied that she introduced them as a new entity, ‘typus Amstelodamensis’.⁵ In 1938 a second article by her hand, again in ‘Archives des Médecine’, revealed a third girl with the same characteristics.⁶ The three girls resembled the case described by Brachmann as far as their secondary characteristics were concerned, in particular the dwarflike status of the children, their facial specificity and the growth of hair. In all these cases, however, also anomalies of the limbs were observed, though not those so characteristic for Brachmanns description: the webbing of both the elbows.

Notwithstanding the fact that, still today, this new entity is sometimes indicated with the eponym of the ‘Brachmann-de Lange syndrome’, the actual fame for the discovery of the first children with this syndrome was for Cornelia de Lange.⁷ The focus of this article is on the historiography of the syndrome, considering the fact that the eponymous fame of De Lange was exceptional against the background of in total 105 women who are, next to thousands of men, registered as medical eponymists on www.whonamedit.com. As Draaisma has

underlined, being honored with eponymous fame was not only a matter of doing pioneering research, but as well of possessing the professional prestige to be able to publish your findings in leading international journals in the field and to receive the credits for the discovery.⁸ This paper outlines the way Cornelia de Lange came to perceive the first cases of children with this syndrome. Furthermore, the aim is to analyze the factors that contributed to De Lange's success in gaining eponymous fame. Thus, this research can be placed in the developing domain of syndrome history that already includes research on children with anomalies such as autism⁹, Asperger syndrome¹⁰, the syndrome of Gilles de la Tourette¹¹ and Attention Deficit Hyperactivity Disorder¹².

The first 'typus Amstelodamensis' girls

The hirsute and dwarf-like little boy that Brachmann had examined in the Dresden hospital after the boy died, was primarily remarkable to Brachmann for his so-called 'Flughautbildung' (webbing) of both elbows.¹³ The photographs of the boy in the article Brachmann published on his research into the case also focus on the anomalies of the arms and hands of the boy. For Brachmann these phenotypical characteristics induced a comparison with only three similar cases in literature which discussed similar anomalies of the elbows. In the conclusion of his article, nonetheless, Brachmann explained the specific deformations in the boys case as caused by 'eine gewisse "Neigung" des ganzen Individuums zu Variationen und Anomalien'¹⁴ When, however, Cornelia de Lange in December 1932 met with her first 'typus Amstelodamensis' girl¹⁵, she was primarily struck by facial aspects of the child such as long dark hair, eyebrows that met at the midline, extremely long eyelashes, low set ears, a tin nose with anteverted nostrils and a not completely developed lower jaw which resulted in a small chin. Subsequently, she described malformations of the limbs, in particular the small hands of the girl with short digits and proximally placed thumbs making them look like 'le pied du signe'.¹⁶ De Lange performed microscopic research on blood and urine and took X-rays as well. Thus abnormality of the skull was revealed, to which De Lange referred as brachycephaly. That the analytical summery of the phenotype of the girls was undoubtedly based on careful observations of children in general is clear from the fact that she also detected behavioural phenotypical aspects in the girl, more precisely 'a développement mental arriéré'. At the time she based this diagnosis simply on behavioural observations without verification through psychological assessment, which could have indicated the degree of intellectual disability.¹⁷

How crucial her meticulous observations of children were for her discovery is clear from the case of a second girl that De Lange outlined in the same article.¹⁸ Within a couple of months after the first girl was noticed, another girl, six months old, was admitted to the children's clinic because of pneumonia. The resemblance between the first and this second girl was so striking that the nurses thought the first girl had returned. After observing the child closely, De Lange concluded that, strikingly enough, the second girl showed the same characteristics as the first one. This time, De Lange mentioned a small mouth with thin lips as another striking aspect. The resemblance with the first girl was, however, that remarkable that De Lange was surprised that children with the same characteristics were never before considered to be the expression of an autonomous entity or a disorder. Since the two children were not related, she assumed she was dealing with two isolated cases. Nevertheless, De Lange was of the opinion that the condition was caused by genetic anomalies. In order to further the knowledge on the phenomenon she emphasized that it was necessary to find new cases for further examination of the syndrome.¹⁹

In 1938, Cornelia de Lange published another article on ‘typus Amstelodamensis’ children, again in *Archives des Médecine des Enfants*.²⁰ Since her first publication, only one new case of a girl, aged ten, had been identified with the same characteristics. This girl was discovered by the Dutch physicians R. Vedder, who was the medical officer of the Amsterdam Paedological Institute.²¹ But also De Lange herself could report about a third girl whom she had seen in the children’s clinic of the University of Amsterdam in 1936. This child was an eleven month old baby who was admitted because her physical development was lagging behind. At first glance it had been clear to De Lange that this child again was a typus Amstelodamensis girl. In addition to facial characteristics common among the three girls she had already diagnosed, this girl showed anomalies of the limbs as well. Now De Lange did not only perform neurological and microscopic research, but she also gathered data in an autopsy on one of the girls she had described in her first article. This child had died at the age of five years and nine months in a mental asylum. No abnormalities were found in the organs of the thorax and the endocrine system. The peritoneum, however, had shown abnormalities that are common among mammals, but not among humans. Furthermore, microscopic examinations of the right hemisphere had revealed a reduced number of brain windings. Again, De Lange was aware that more study was needed to unravel the underlying pathological anatomy of the identified condition.²²

Nevertheless, with both her articles in 1933 and 1938 De Lange had been capable of identifying a new, rather rare condition, she named after the place of the clinic’, ‘typus Amstelodamensis’. In her discovery of the girls her meticulous observations of the common phenotypical anomalies in the children had been crucial. Furthermore, her research in the pathological anatomy of the children’s anomalies had been supportive in unravelling the first knowledge on the endo-phenotype of the girls. Thereby the presumption was that a genetic influence contributed to the anomalous development of these children.²³ And last but not least, De Lange’s open mind and keen clinical eye made her sensitive to notice that the behavioural phenotype of these girls also showed a form of intellectual disability. Subsequently, this aspect was also included in the first representation of what was named the Cornelia de Lange syndrome.

Although occasionally the syndrome is also referred to as the Brachmann-De Lange syndrome, the eponymous fame for the discovery of the syndrome is mostly given to De Lange. When Berg, McReary, Ridler and Smith in 1970 published a first monograph on *The De Lange Syndrome*²⁴, they stipulated the difference between on the one hand Brachmann’s account in 1916 of the case of the boy in whom he underlined anomalies of the limbs and, on the other hand, De Lange’s observations in the 1930s of the three girls with common anomalies among which those of the limbs. In their monography Berg and others refer to an 1965 article by Choo and Bianchi, who pointed out the advantage of having no possible confusion with another syndrome described by De Lange in 1934, concerning, however, an unrelated condition.²⁵ Next to the fact that Brachmann’s focus on the limb-anomalies was far from the endo- and behavioural-phenotypical aspects which Cornelia de Lange had first noticed as important in the typus Amstelodamensis girls, Brachmann made no further contribution in establishing new facts about the syndrome. The main reason for this was that he shortly after his first publication ceased his efforts in medical research. Furthermore, Berg and others even doubt whether the boy whom Brachmann described in his article actually had been a typus Amstelodamensis child as discovered by De Lange in the 1930s. During the 1940s and 50s, however, various new cases of children with De Lange syndrome were discovered and the publication of the first data on these children in various international

journals enabled medical researchers in the 1960s to detect many more examples of children with the same condition.²⁶

Pioneering in pediatrics

Physicians who were active in the last quarter of the nineteenth century and the first quarter of the twentieth century had, according to Draaisma, the best prospects of being honored with an eponym.²⁷ In that time span, however, women physicians were scarce, only starting medical practice, abroad as well as in the Netherlands, in the last part of the nineteenth century.²⁸ These women physicians mainly worked in the domain of women's and children's health, since this was thought to match their feminine qualities. Thus, many academic careers of women started off in medical activities concerning women, in particular also as mothers, and their children. As Watts has noted, 'connections with the home and especially childbirth, medicine long offered women their chief pathway into science'.²⁹ For Cornelia de Lange as well, the route into an academic career went through a life as a practitioner for women and children.

Born in 1871 in Alkmaar as the eldest of three in a prominent family, Cornelia de Lange received a solid education.³⁰ Against objections of her parents who sent her abroad after high school in the hope she would change her mind about going to university, De Lange studied, first chemistry and later medicine. In 1897, she passed her medical qualifying examination at the University of Amsterdam and a few months later she finished her dissertation on the theme of lactation.³¹ At her university she was the second woman defending her thesis, while in the Netherlands only the fourth woman receiving this academic status.³² Subsequently, she developed in the speciality of children's diseases during a period of study at the Zürich Children's Hospital with Oskar Wyss. After her return to Amsterdam in 1899, she became a practitioner, focussing on women and children. In addition she started to assist Alexander Voûte in his clinic for children's diseases.

In these years around the turn of the century her engagement in circles of social care in the Dutch capital of Amsterdam increased, not in the least because she had met with Johanna ter Meulen, the first Dutch housing inspector. They even went to live together.³³ De Lange also had taken up the medical responsibility for the Amsterdam home for unwed mothers 'Beth Palet'. At the important feminist event of these days, the 1898 National Exhibition of Women's Labour, De Lange spoke about 'The task of mothers and women educators. Moreover, she put her medical professionalism in service of writing about the state of nursing practices in Dutch hospitals and published on the theme in the journal of the National Exhibition.³⁴ With Jeltje de Bosch Kemper and the Amsterdam department of 'Tesselschade', a prominent women's organisation within the women's movement of those days, De Lange initiated a kindergarten project as well as professional training for teachers in kindergartens. In 1908 she got involved in the Dutch Federation for the Protection of Infants and in 1911 she was a co-establisher of the Amsterdam Association of Infant Care, which initiated a health centre and lessons in child hygiene, care and infant nutrition. Next to popular publications on infant care, De Lange was the driving force behind the Dutch journal on childcare (*Tijdschrift voor Kinderverzorging*), first published in 1907.³⁵ All these activities showed Cornelia de Lange's increasing commitment in the world of female activism which accompanied the development of the women's movement of the turn of the century in the Netherlands.³⁶

At that time paediatrics as a specialty was still in its infancy. In the Netherlands renewals in health care started off slowly. The interest in children's health developed only in the second half of the nineteenth century. In 1863 the Sophia Children's Hospital was the first to open doors, aiming at both the care of children and research into children's diseases and special needs.³⁷ Infant mortality remained an important factor in the development of paediatrics, since this was still high in the second half of the nineteenth century due to bad hygiene and malnutrition. Around the turn of the century scientific solutions were sought, resulting among other things in a couple of dissertations, including that by Cornelia de Lange on nutrition disorders and the improvement of artificial nutrition for infants.³⁸ De Lange's career was build up in the period of the rise of paediatrics as a distinct speciality, something she vigorously campaigned for.³⁹ In 1898 De Lange became member of the Dutch Society for Paediatrics, which was established in 1892. The struggle to establish paediatrics as a separate discipline within medicine was not progressing rapidly. Only in 1909 the first Dutch professor in paediatrics was appointed at the University of Groningen. In the meantime, however, De Lange had received a position as head of the new ward for infants at the Emma Children's Hospital in 1907. This enabled her to examine all kinds of diseases among children. Next to publications on infant nutrition and infectious diseases, she had already written popular books on infant care and hygiene and made publications on soufflés, diseases of the blood, abdominal ailments and diabetes, on which treatment did not yet exist at the time.⁴⁰ With her appointment at the clinic, she received the opportunity to do more extensive research and gradually her interest shifted towards neurology, a domain that, comparable to paediatrics, was developing those days. Like De Lange, most physicians of those early generations did their own neuropathological work-up and diagnosis since neurology as a distinct speciality did not yet exist.⁴¹ The first sign of De Lange's interest in neurology inclined topics was a publication on neuropathy in 1905, followed by publications in 1912 on acute cerebral tremor and an overview article on literature about spasms and paralysees with whooping cough in 1912.

Next to advances in microscopy, De Lange started to perform autopsies on deceased children, in cooperation with J.C. Schippers.⁴² In a series of articles in the late 1910s and the 1920s on the pathology of the first months of the life of children, she was often faced with congenital anomalies. She published articles on congenital spinal paralysees (1920), total and partial lack of the corpus callosum (1924), histopathology of the spinal cord with congenital syphilis (also in 1924), microcephalie (1925) and congenital anomalies of the urinary tract (with Schippers in 1927). After having studied the pathological anatomy of these clinical pictures, De Lange advocated cautiousness with diagnosing infants with congenital diseases and cerebral anomalies, since many cases had yet shown the diagnosis to be different than the one presumed. Difficulties a physician can encounter in diagnosing anomalies of the central nervous system can be found in de Lange's article on congenital tumour of the mediastinum, in which she traced back clinical neurological symptoms to anatomical anomalies of the nervous system. In her work as a paediatrician Cornelia de Lange showed a growing awareness of these diagnostic difficulties which she also had encountered in her own daily practice. She stated that 'experience has taught that the first weeks of life of the child can be rich in clinical pictures, which sometimes too much of our diagnostic abilities'.⁴³ Since autopsies, next to other research, could reveal unexpected findings, she was of the opinion that 'physicians who are frequently checked on their diagnostics by pathologists, can not be grateful enough for this privilege, it teaches them modesty'.⁴⁴ Also the collaboration with geneticists in finding answers on questions concerning heredity was something De Lange propagated.⁴⁵

Presumably, not only an increasing interest in congenital anomalies of the nervous system sensitized De Lange's attention for children with typical anomalies, eventually leading to her discovery of the three similar anomalous girls. Her sharp observational skill, based on a firm conviction that research in paediatrics required a specific attitude in dealing with children, was of crucial importance. Diagnosing children's symptoms required both a specific attitude and the knowledge to contextualize the condition of the child as part of its development and the social situation. This argument had been valid for De Lange since the moment she started to advocate paediatrics as an autonomous field within medicine. Already in her dissertation, in 1897, she pointed out 'the right for paediatrics to be a specialty'.⁴⁶ In the treatment of children, attention for the pedagogical interaction was imperative, according to De Lange. 'If a doctor has any understanding of upbringing, he will, in particular to children, prescribe less possible medication, for every draught or box of powders will focus the attention of the child to its illness', she once declared.⁴⁷ Her point of view that a pedagogical perspective was needed to properly diagnose and treat children with diseases was a vital element in her inaugural speech in 1927, when she accepted her chair in paediatrics at the University of Amsterdam. She noted that neuro-pathological cases among children had become more prevalent than ever before and treatment could often be found in 'orthopaedics of the mind rather than the body'.⁴⁸ In a retrospective on her career in a Dutch journal for paediatrics in 1947, De Lange noted that an accurate diagnosis of a child's condition required both the time to do a proper observation and the ability 'to read an infant'.⁴⁹ Already in 1940, she had published in the same journal an article entitled 'Without hammer and stethoscope', arguing that meticulous observation of children would enable doctors to recognize a normal from an anomalous child.⁵⁰ Thus, De Lange was a forerunner trying to understand the individual child and child development in general. Even though paediatricians, also in the Netherlands, had initiated the practice of giving special attention to children's medical needs, only a couple of them managed to integrate pedagogical attention in their medical approach.⁵¹

The career of a woman doctor

Yet not only her thorough research and her pioneering role within pediatrics may explain De Lange's success in receiving eponymous fame for her work on the three Amstelodamensis girls. As Draaisma has argued in his study on medical eponyms, the fame for a discovery is dependent too of publication of the phenomenon in a prominent medium for scientific communication. Only if the new data are shared with respected colleagues who, subsequently, are recognizing them as valuable, a certain consensus is created which legitimates the existence of the new phenomenon.⁵² In this process of recognition the name of the discoverer is attached to the new entity. When others started to refer to the new name of the entity, an eponym is born. So, the birth of a syndrome is not only about serious research efforts, but as much about gaining scientific prestige, based on professional status and a certain reputation. Yet for women physicians this was no sinecure. Like in the rest of Europe, in the Netherlands women entered the field of medicine only towards the end of the nineteenth century.⁵³ By then a preference for descriptive denominations had set in into the medical world. Consequently, honoring physicians with an eponym was already over its highest point by the time women became actors of significance within the medical field.

Cornelia de Lange had started her career as a pediatrician after her stay in Switzerland in 1899. The new domain had steadily evolved abroad, which made Dutch pioneers in pediatrics visit universities and clinics in Germany, Switzerland and Austria. There they acquired new knowledge to profile their domain. To catch up with international developments in the field of

child medicine around the turn of the century, the Dutch Society for Pediatrics filed with the government a special request for the official recognition of pediatrics as a distinct specialty which resulted in the first Dutch professorship for pediatrics in 1909.⁵⁴ The Dutch Society for Pediatrics, of which De Lange was a member since 1908, had aimed at improving contact between physicians interested in pediatrics, to facilitate the circulation of knowledge and to raise the level of practicing child medicine in the Netherlands. De Lange contributed to this process when she, as head of the infant ward at the Emma Children's Hospital in Amsterdam, became involved in the Dutch Journal of Medicine (*Nederlandsch Tijdschrift voor Geneeskunde*). First she was a staff member of the journal and from 1913 onwards also an editor. In these years she had started to make publications in cooperation with Jan Schippers, the managing director of the clinic, who decided to make De Lange his interim. Thus she combined research with practicing child medicine and when eventually in 1927 Jacob de Bruin, the first full professor in pediatrics at the University of Amsterdam, died, De Lange was the obvious person to be his successor. She hesitated, however, for this position would connect her to another hospital. Besides, the domain of pediatrics was still very much developing. In the end she accepted and became the first Dutch female full professor in the Netherlands.⁵⁵

De Lange built up her professional success in medicine in the first decades of the twentieth century with an active participation in the domain of science, both as a researcher who published her work widely and as a member of editorial staffs and boards, giving lectures and talks and inspiring other doctors with her ideas about child medicine. Her list of publications, with over three hundred items, reflects her increasing status as an international respected researcher in pediatrics.⁵⁶ Her first international publications, on the theme of her dissertation, infant nutrition, dated back to the first years of her career and were written in German. From the 1910s onwards, De Lange also started to publish in other languages such as English and French.⁵⁷ After her editorial membership of the Dutch *Acta Paediatrica* in 1924, she became an editor of *Annales Paediatrica* in 1938. The journal was a continuation of the *Jahrbuch für Kinderheilkunde*, in which De Lange had her first international publications. In 1933, she had been the Dutch government representative at the International Conference for Paediatrics and from that time onwards she also became corresponding member of the department for Pediatrics of the Royal Society of Medicine in the United Kingdom. At the occasion of her 75th birthday, the editor of the *Annales Paediatrica*, Ernst Freudenberg, underlined her professional prestige by stating: 'In this specialty she belongs beyond any dispute to the first authorities within the field.'⁵⁸

Her professional authority is visible in the prominent role she came to play in the Dutch Society for Pediatrics.⁵⁹ She had been the first woman member of the Society, admitted even before the turn of the century.⁶⁰ Only into the first decade of the twentieth century, more women doctors were invited to participate in the Society.⁶¹ Next to many contributions to debates on case histories in the yearly Society meeting, De Lange delivered her input in organizational activities. In 1908, for example, the Society discussed her proposal to start a small library around specific international journals and to appoint a member as the librarian of this collection.⁶² In 1911, the Society elected De Lange as one of its board members for five years.⁶³ In 1917, subsequently, she was included in a commission that had to contribute from a pediatric point of view in the change of the law on contagious diseases. Her increasing international commitment is apparent from the fact that she, in 1922, pleaded for a more active participation in a cooperative meeting with the German sister society.⁶⁴ By 1929 her influence had expanded in a way she could be chosen president of the Dutch Society.⁶⁵ She was in charge until the summer of 1935.⁶⁶ During her presidency the Society was involved in

a struggle for recognition of the domain of pediatrics as an autonomous discipline in its own right, which was successful in 1935.⁶⁷ As Marland in her account of the first generation of women physicians in the Netherlands has emphasized, Cornelia de Lange was not only the ‘first and foremost “professional”, in career terms’, as well she was the most ‘outstanding’ among the first generation pioneer women doctors such as Aletta Jacobs and Catherine van Tusschenbroek. She was a real “honorary man” in the professional community and abroad. This was not only highlighted by the professorship she received, but as well by a knighthood that honored her work.⁶⁸

In contrast to women Jacobs and Van Tusschenbroek, both also active in the domain of medicine for women and children, De Lange was not much involved in the women’s cause. Her professionalism seemed to prevail when matters of gender relations were at stake. As Marland has noted, De Lange ‘had little interest in women’s issues and her views on most points are indistinguishable from those of her male colleagues’.⁶⁹ There was, however, an intrinsic relationship between on the one hand De Lange’s knowledge about women and children’s health and well-being and on the other hand the way she shaped her professionalism within medicine. By what can be indicated as ‘professing gender’⁷⁰, she was profiling the domain of pediatrics not so much as a women’s issue in its own right, but as a domain in which gender mattered. In the first place De Lange was well aware of how gender relations structured the medical practice of her days. Secondly, she started to apply values and develop attitudes which were traditionally connected to women in order to improve the treatment of children and to enhance debates and research in the developing field of pediatrics. Her professorship enabled her to stimulate research in pediatrics and three of the fourteen dissertations she supervised during these years from 1927 until 1938 were by women. At the end of her career, in a speech in celebration of the 30th anniversary of the Dutch Association for Women with an Academic Education in 1948, De Lange recognized that success for women in research still was exceptional. ‘In pure scientific research men will remain superior to women’, she explained, ‘not because of men’s better intellectual capacities, but for women’s physical endurance and her lack in motivation’. Besides, according De Lange, ‘many women have been working in subordinated positions, which did not enable them to fully develop’.⁷¹ In the Dutch context women physicians were marginal at first.⁷² Nevertheless, at the end of her career, De Lange noticed that women doctors no longer were regarded a problem, in particular not the ones without spouses and off-spring. On the contrary, practicing medicine was seen as a new opportunity for unmarried women to have a rich and full filling task in life.⁷³

Notwithstanding the gradual changes in gender relations within the field of medicine, the prototypical pediatrician in the first decades of the twentieth century had been a man, although a man with specific characteristics. As De Lange formulated:

‘The pediatrician lives his days among children; this keeps him amazingly young though his hairs are gray. He has something in his face that attracts children. [...] it has to be something in his eyes; in these eyes children have to detect something of their own world. The pediatrician has to be someone who is not financially demanding, for his specialty will not bring him great profit. Yet he would not want to change it. And from a scientific point of view, and socially, it gives him full satisfaction.’⁷⁴

Thus, a pediatrician, though being a male, had characteristics that were close to femininity in the sense of being a caring professional who was close to patients, in particular because they were children in the case of pediatrics. After all, women’s vocation was at the beds of the ill.

‘Guérir quelquefois, soulager souvent’, De Lange questioned, ‘is not this a duty completely in line with femininity?’⁷⁵ This femininity, included in commitment and caring power towards both patients and children, was what made pediatrics, like education, such a beautiful vocation for women.⁷⁶

Conclusion: the only Dutch female eponym

When Cornelia de Lange in the early 1930s observed the first little girls who showed symptoms she did not immediately recognize as a known entity at the time, she already was a well established doctor, both in her practice as a doctor in child medicine and as a respected professor in pediatrics. At the time she was chair of the Dutch Society for Pediatrics and it was in these prestigious circles that she discussed the cases of the girls.⁷⁷ Then she had already published her data about these anomalous children, indicated as ‘typus (degenerativus) Amstelodamensis’, in the prominent French journal *Archives des Médecine des Enfants*. By now her reputation as a respected medical scientist had been established through a phenomenal rate of publications, both national and international. Her research was honoured for its accuracy, its detailed descriptions and the use of new medical techniques.

During her career, De Lange worked on the shift of two new domains, that of pediatrics and neurology. She meticulously observed the phenotype of her patients in order to trace back observable clinical neurological symptoms to anatomical anomalies of the central nervous system. De Lange, however, was not only a technically and scientifically excellent physician, she was also a good pediatrician in paying attention to the well-being of for her little patients and their parents. She was amongst a small group of pediatricians who tended to recognize the importance of both child psychology and pedagogical topics in their observations and treatment. Thus, she could see the uniqueness of each child and made her susceptible for the combination of characteristics, among which their limited mental development, which enabled her to notice the three Amstelodamensis girls.

There is no evidence that Cornelia de Lange has ever noticed the resemblance between her observations of the first Amstelodamensis girls and Brachmann’s little boy, who died too early to be diagnosed in a way De Lange would have wanted to diagnose an anomalous child. At the time, in the first decade of the twentieth century, physical anomalies of the limbs, and in particular the deformed hands and the wing-like deformation of the arms, were the focus in examining the boy, whom Brachmann generally recognized as an individual having a tendency towards anomalies. The first physician who observed a case of a child with Cornelia-de-Lange syndrome had been R. Vedder, a Dutchman as well, who published an on the ten year old child in 1935.⁷⁸ In 1939 a first Italian child with Cornelia de Lange syndrome was found, while the 1940s and 1950s brought several new cases in various countries within Europe.⁷⁹ These cases were identified, for example in 1957 by Ernst Zweymuller, doctor at the University Child Clinic in Wien, as ‘Neue beobachtungen an einem Typus degenerativus Amstelodamensis (Cornelia de Lange)’.⁸⁰ When in the 1960s, however, based on developments in genetics, various new observations were made of children with the syndrome, Opitz noticed on the one hand that this ‘raises the suspicion that the Cornelia de Lange syndrome may not be as rare as initially suspected’.⁸¹ On the other hand he pointed at the discovery of Brachmann in the early twentieth century, stating, however, that at this later date ‘it may be confusing to introduce the term *Brachmann-de Lange* [italics in the source] syndrome’.⁸² In 1964, also the *British Medical Journal* published an editorial comment on ‘Amsterdam dwarfs’, identified the De Lange syndrome as a ‘well-defined entity, hitherto

scarcely noted' and regarded Cornelia de Lange to be the person who 'first recognized the syndrome'.⁸³ Her actual eponymous fame came from the first monograph on *The Cornelia de Lange Syndrome* by Berg and others in 1970. They pleaded for naming the disorder after De Lange because 'Brachmann's report, though unusually detailed in some aspects, lacks the comprehensive and illuminating quality which distinguished De Lange's contributions to the subject'.⁸⁴

Not many women were successful in gaining eponymous fame and Cornelia de Lange remained the only Dutch female eponym in history. In her case gender was not structuring her potential as a female professional in the world of medical science simply in a negative way. De Lange became, against the odds of her time, not only a physician, but as well a medical researcher who was successful in performing and applying new medical techniques. Furthermore, she positioned herself in the centre of two niches in medical science that gradually developed into important new domains at the end of the nineteenth and in the first decades of the twentieth century. Both pediatrics and neurology were not established medical fields in which many other and mostly male doctors were competing for professional status. Yet, this was not the only gender characteristic that enhanced De Lange's success. As important was her professional power to care for her patients, more in particular children. Her persistent conviction that pedagogical attitudes had to be taken into account, added to her engagement in activities of social care, in particular for women as mothers and their infants, shaped her professional potency and made her a devoted scientist with her feminine heart closely connected to her intellectual capacities and her accurate clinical eye. This may be underlined by the way her feminine way of profiling her professional identity as a doctor and a pediatrician was typified in one of the obituaries after her death in 1950: 'She was a trailblazer, without ever really "blazing"'.⁸⁵

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- ¹ Bogdan, 1988; Garland Thomson, 1996; Trent, 1998.
- ² Leroi, 2003.
- ³ Brachmann, 1916.
- ⁴ <http://www.whonamedit.com/doctor.cfm/1060.html>
- ⁵ De Lange, 1933.
- ⁶ De Lange, 1938.
- ⁷ Nowadays Cornelia de Lange syndrome is described as ‘a genetically determined congenital syndrome characterised by a specific facial appearance, limited growth of both head circumference and height, malformations of several organ systems, developmental delay, and behavioural problems’. Wulffaert et al, 2009, (in press).
- ⁸ Draaisma, 2006.
- ⁹ Houston and Frith, 2000; Frith, 2003; Neumärker, 2003; Wolff, 2004.
- ¹⁰ Wing, 1998; Draaisma 2006.
- ¹¹ Kushner, 1999; Draaisma, 2006.
- ¹² Rafalovich, 2004; Smith, 2008.
- ¹³ Brachmann, 1916, 227-229.
- ¹⁴ Brachmann, 1919, 234.
- ¹⁵ In naming the girls this way she followed a common practice in bacteriology, according to Berg et. al.1970, 3.
- ¹⁶ De Lange, 1933, 718.
- ¹⁷ De Lange, 1933, 715.
- ¹⁸ De Lange 1933, 717.
- ¹⁹ De Lange 1933, 719.
- ²⁰ De Lange, 1938.
- ²¹ Vedder, 1935.
- ²² De Lange, 1938.
- ²³ The cause of the syndrome was recently found in mutations one of three specific genes. In case mutation is absent, diagnostics are based on a system developed by members of the Clinical Advisory Board of the Cornelia de Lange Syndrome Foundation USA and the Scientific Advisory Committee of the World Cornelia de Lange Syndrome Federation. Clinical findings should meet minimal diagnostic criteria within several body-system-categories such as facial characteristics, growth, and developmental and behavioural criteria. See Kline, Krantz, Sommer, Kliewer, Jackson, Fitz-Patrick, Levin & Selicorni, 2007.
- ²⁴ Berg, McCreary, Ridler, Smith, 1970.
- ²⁵ Choo and Bianchi, 1965; De Lange, 1934.
- ²⁶ See for example: Richter, 1961; Ptacek, Opitz, Smith, Gerritsen and Waisman, 1963; Jervis and Stimson, 1963; Geudeke et al., 1963.
- ²⁷ Draaisma, 2006, 10.
- ²⁸ Marland, 1995, 449.
- ²⁹ Watts, 2007, 3.
- ³⁰ See for more biographical information De Knecht-Van Eekelen, 1990 and De Knecht-Van Eekelen and Hennekam, 1994.
- ³¹ De Lange, 1897.
- ³² Poelstra, 1990, 18.
- ³³ Van Drenth, 1995.
- ³⁴ Van Drenth, 2007, 166.
- ³⁵ Van Drenth, 2007, 167.
- ³⁶ See for the notion of ‘female activism’, Van Drenth and De Haan, 167. See for a broader European context of women and achievement in the nineteenth century Clark, 2008, in particular Chapter 4 ‘Caring and power’ 125-159.
- ³⁷ Van Lieburg, 2004.
- ³⁸ The growing attention for child welfare was eventually reflected in the establishment of the Dutch Confederation of the Protection of the Infants in 1908.
- ³⁹ Marland, 1995.
- ⁴⁰ A list of over 315 publications was added as a supplement (Bijlage II) to de Knecht-Van Eekelen, 1990, 61-79. At De Lange’s 75th birthday a brochure listing her publications. See *Titels van de Wetenschappelijke geschriften van Prof. Dr. Cornelia de Lange*. (with a foreword by B. Brouwer).
- ⁴¹ Koehler, Bruyn and Moffie, 1998.
- ⁴² De Knecht-Van Eekelen and Hennekam, 1994, 258.
- ⁴³ De Lange and Schippers, 1922, 950.

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- ⁴⁴ De Lange, 1931, 551.
- ⁴⁵ De Lange, 1927.
- ⁴⁶ De Lange, 1897. Next to this proposition the thesis included two others with a pedagogical accent: one concerning schools for ‘idiot and retarded’ children and on the preferable age for children to enter primary education.
- ⁴⁷ Quote in De Knecht-Van Eekelen, 1990, 21.
- ⁴⁸ De Lange, 1927, 14-18, quote on 17.
- ⁴⁹ De Lange, 1947, 240.
- ⁵⁰ De Lange, 1940, 488-491.
- ⁵¹ Van Lookeren Campagne and Boekhold, 1942.
- ⁵² Draaisma, 2006, 8.
- ⁵³ Marland, 1995.
- ⁵⁴ Van Lieburg, 2004.
- ⁵⁵ Bosch, 1994, 29 and 135.
- ⁵⁶ De Knecht-Van Eekelen, 1990, Bijlage II, 61-79.
- ⁵⁷ *Titels van de Wetenschappelijke geschriften*, 7-19.
- ⁵⁸ Quote in De Knecht-Van Eekelen, 1990, 45.
- ⁵⁹ See for the history of the Society: Van Zeben, 1982. The official name of the Society changed in 1922 from ‘Paediatric’ into ‘Kindergeneeskunde’.
- ⁶⁰ Archives of the Dutch Society for Pediatrics (Nederlandsche Vereniging voor Paediatric): Notulenboek II (1899-1911).
- ⁶¹ In 1905. for example, De Lange is amongst one of four members proposing a new woman doctor as a member: Mej. Dr. J. Henriëtte Schagen van Soelen, physician at the Hague. Notulenboek II, 25 November 1905.
- ⁶² This was not very successful, however. According to De Knecht-Van Eekelen, 1990 (56, note 51) the initiative remained restricted to the publication, in 1909, of a catalogue of literature on children’s diseases available in Dutch public libraries.
- ⁶³ Notulenboek III (1911-1929), 25 November 1911.
- ⁶⁴ Notulenboek III, 13 Mei 1922.
- ⁶⁵ Notulenboek IV (1929-1939), 6 Juli 1929.
- ⁶⁶ Notulenboek IV, 6 Juli 1935.
- ⁶⁷ De Knecht-Van Eekelen, 1990, 36-39.
- ⁶⁸ Marland, 1995, 449. How exceptional De Lange’s professorship was is clear from the fact that in 1940 only seven women held professorships in the Netherlands, of whom two medical. Next to Cornelia de Lange (1927 full professor in pediatrics at Amsterdam University), Charlotte Ruys received an extraordinary professorship for microbiology and infectious diseases at Amsterdam’s public health department in 1940. See Marland, 1995, 461.
- ⁶⁹ Marland, 1995, 450.
- ⁷⁰ The concept of ‘professing gender’ (as giving meaning and value to femininity within a professional practice) is inspired by Lunbeck, 1994, 24-25. See also Van Drenth and Van Essen, 2008.
- ⁷¹ De Lange, 1948, 14.
- ⁷² Bosch, 1982.
- ⁷³ De Lange, 1949, 211.
- ⁷⁴ De Lange, speech in Van Zeben, 1982, 42.
- ⁷⁵ De Lange, 1949,
- ⁷⁶ Van Drenth, 2007, 170-171. See for the intrinsic relationship between femininity, maternalism and caring power: Van Drenth and De Haan, 1999, 169-170. See also Koven and Michel, 1933 and Marland, 1992.
- ⁷⁷ Notulenboek IV, 28 November 1937.
- ⁷⁸ Vedder, 1935.
- ⁷⁹ Ptacek et al., 1963. 100-1001. They signalise a total of 16 cases of children with Cornelia de Lange syndrome over the world at that time.
- ⁸⁰ Zweymüller, 1957.
- ⁸¹ Opitz, 1964, 502.
- ⁸² Opitz, 1964, 504.
- ⁸³ Leading article in the *British Medical Journal*, 1964, p. 326.
- ⁸⁴ Berg et al, 1970, 4.
- ⁸⁵ Van Westrienen, 333-336.