

# Biopower and the Construction of an Ethnic Disease (Based on the Example of the Kashubians)

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## Abstract

The notion of biopower implies managing populations by regulating and controlling life-related processes. This power medicalizes society, and, in the age of genetics, a unique role is played by genetic research. This has led to the discovery of new diseases such as LCHAD enzyme deficiency, the occurrence of which is relatively more frequent in the Kashubian population. In this case study, I present the process of constructing this rare genetic disease into an ethnic disease. A significant role in this was played by doctors and journalists who, by means of cultural capital, symbolic violence and the power wielded by news media, spread the term the “Kashubian gene,” thereby suggesting that the disease is common in this ethnic-regional group. Despite the adverse effects, the process also had positive consequences: it contributed to the introduction of screening tests for newborns aimed at diagnosing the disease, thereby saving human lives.

## Key words

LCHAD, biopower, ethnic disease, “Kashubian gene”

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I began to examine the issue of biopower in the years 2016–2017 while researching the sociocultural effects of LCHAD deficiency.<sup>1</sup> Although it is a rare disease, it relatively more frequently occurs in the Kashubian population (Piekutowska-Abramczuk et al. 2010; Nedoszytko et al 2017). Subsequently, my attention turned to the role played by doctors in the process of problematizing and constructing the risk of the occurrence of this disease in this ethnic-regional group. Modern medicine and genetics are not only interested in the disease, but also the risk of its appearance and the measures necessary to reduce its occurrence. Hence, groups in which a particular disease is more prevalent are covered by various forms of surveillance and control (Clarke et al. 2009: 24). This process, which, in this case, is an element of biopower (Rose 2007; Foucault 1998), consisted of genetic screening tests carried out for newborns and for families in which a case of the disease had occurred. Biopower has changed the role of doctors, as they are no longer officers in the service of the state that disciplines and controls the health of society through the standards it imposes. Instead they are largely experts in the medical discourse that penetrates the collective consciousness. As a result, laypeople are able to internalize medical advice and assume more responsibility for their health (Nye 2003: 117; Nowakowski 2015: 44).

At the core of these discursive practices are often relationships of domination and submission that medicalize society and “create” disease. In this case study, with regard to the notion of power-knowledge (Foucault 1998: 29), doctors played an important role in the social construction of this “ethnic disease”. Alongside doctors, the second professional group that contributed to the creation of the ethnic disease attributed to the Kashubians were journalists, who spread the non-medical term for the disease.

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1 This article expands on the issues presented in the article “Social Consequences of Identifying a Genetic Disease with an Endogamous Ethnic Group: The Kashubian Case” (Kwaśniewska 2022) in which I show the impact of LCHAD enzyme deficiency, also known as the “Kashubian gene”, on the identity of this ethnic group. The disease has become a kind of stigma and “broken identity”. The article shows that the new biomedical identity associated with the disease is either accepted, negotiated, or, on account of its stigmatizing properties, ignored by Kashubians.

In this article, I focus on the role that doctors and the press played in the popularization of the term “Kashubian gene”. The authority of doctors and the power of the modern news media, especially the press and the Internet, allowed a non-medical, labeling term to become commonly used. It shows that a significant role in this process was played by the field of power-knowledge and the symbolic violence of groups with higher cultural capital that have access to various media against a group with lower cultural capital.

I adopted the concept of biopower by Michel Foucault as the theoretical framework for this article. According to the French scholar, we live in an era of biopower. This era emerged at the end of the 18th century in the aftermath of epidemics that plagued European societies and with the need to counteract their effects (Foucault 1999: 48–50). It then went on to penetrate society. Today, it no longer means that doctors exercise direct rigorous control over society, but rather they penetrate the collective consciousness via medical discourse. Foucault linked discourse with power; he saw the process of discourse production and distribution as dependent on and in the service of (bio) power (Foucault 1981). Biopower is a scattered, invisible power that targets the bodies of individuals and populations and aims to shape them, both from the outside and on the inside. According to Foucault, biopower focuses primarily on “life itself” (Foucault 2006: 523–527).

Paul Rabinow and Nikolas Rose expanded on Foucault’s concept of biopower. They also noted that biopower encompasses strategies of intervention in the name of the life and health of entire ethnic, national, or religious groups, as well as new ways of empowerment (Rabinow – Rose 2006: 197). Pierre Bourdieu’s concept of symbolic violence (Bourdieu 1990) is also relevant in this context. According to Bourdieu, a social or professional group can exert symbolic violence when it has a significant cultural and symbolic capital that allows it to influence other groups through its status, language and field of power. Doctors and journalists make up such a group. Eliot Freidson, who dealt with the issue of the social creation of disease and the profession of doctors, drew attention to the ability of the medical community to shape and maintain a dominant position in society (Freidson 1970). This dominance is related to the autonomy resulting from the ability to direct one’s work. Autonomy is the result of doctors’ medical knowledge and professionalism. Knowledge and professionalism allow doctors to make decisions regarding individual cases (patients). Critics of the professional dominance of physicians note that their autonomy has been eroded due to the loss of their monopoly on medical knowledge and diminishing paternalism towards patients (Wolinsky 1988: 33–37).

The article aims to show that creating LCHAD deficiency as an ethnic Kashubian disease is related to biopower. Doctors and journalists have played an important role in this, as a result of the status of medicine, the role of the media and the symbolic violence of groups of higher social status against groups of lower status. In the analyzed case study, biopower manifests itself both in the discourse on LCHAD deficiency in the Kashubian population and the methods of medical supervision (the screening of newborns). Another aim is to show how biopower has interfered in the

sphere of Kashubian culture and marriage customs. It will also demonstrate the role of journalists who specialize in medical topics, and genetics in particular. Through the media discourse, they contributed significantly to the dissemination of the non-medical term for the disease, “the Kashubian gene”, thereby assigning it the status of an ethnic disease. It also shows the positive side of biopower and the process of “sentencing one to live”, which, by introducing screening tests for newborns, led to the early detection of cases of LCHAD, which has ultimately saved human lives. Methods of resistance to biopower are also discussed.

## Research

The empirical basis of this article is provided by data obtained during the research I conducted between 2016 and 2017. It was interdisciplinary research, in which various research methods were used. One method was a content analysis of pre-existing data with elements of critical discourse analysis (CDA). I found 30 articles on LCHAD deficiency in the Kashubian population published between 2006 and 2017 in the local and national press and on the Internet. CDA studies social processes and interactions that often take on linguistic form, perceiving discourse as a form of “social practice” and presuming the existence of a relationship between discursive events and the situations and institutions that frame it (Fairclough – Duszak 2008). Discourse establishes certain conditions, identities, and relationships between people. Since discourse has such a great social impact, it is connected with issues of power. Discursive practices can create and reproduce unequal power relations, such as racist discourse and relations between ethnic groups. Language plays an essential role in discourse, which, according to Pierre Bourdieu, is not a neutral, but a structuring medium. Its influence in this respect depends on the actor’s position in the social field or power relations (Bourdieu 1991: 105–106).

The second method was in-depth interviews conducted with Kashubian people living in Kartuzy and Puck counties in 2016 and in Bytów and Wejherowo counties in 2017. These regions were chosen intentionally, because they have been inhabited by Kashubians for centuries. I conducted 24 interviews with people from Kashubian families (aged 24–76, 11 women and 13 men) living in the villages of Kolonia, Staniszewo, Sianowo, Mirachowo, Sierakowice, Wilanowo (Kartuzi county); Kosakowo, Swarzewo (Puck county); and Bieszkowice and Szemud (Wejherowo county). The in-depth interviews were designed to ascertain the views and attitudes of Kashubian people and ethnic community leaders towards the disease, the reception of the terminology, and also forms and methods of resistance.

The third method was participant observation. I participated in conferences addressing patients with rare diseases, including LCHAD deficiency, in Wejherowo, and a conference in Gdańsk for doctors dealing with LCHAD deficiency, which was aimed at the Kashubian scientific community.

### **What is biopower?**

According to Foucault, biopolitics is a modern manner of governing, a specific state-level way of organizing the life of a population, and biopower is the technology of exercising power (Foucault 1998: 240). (However, Foucault used these terms interchangeably). Foucault distinguished three types of power. The first is the sovereign power over a territory and its products. He believes it originated in the Middle Ages and reflected the power mechanisms of feudal monarchy. This power focused on the appropriation of goods, products and services. In extreme cases, it could be the arbiter of the life or death of its subjects. It also eradicated groups considered undesirable, by means of genocide, for example.

The second type is the disciplinary power that is in opposition to the rule of the sovereign. It emerged in the 18th century and chose the body (bodies), time and work as its objects. It is a power constantly exercised by overseeing what bodies do and appropriating their time. This power was exercised by a system of control, hierarchy, inspection, written reports, and “disciplinary labor technology” (Foucault 2006: 523). Disciplinary authority strives to rule over a multitude of people, composed of individual bodies that must be supervised, trained, used, or punished (Foucault 2006: 524). This power emerged in the era of capitalism, and it aimed to shape the “quality” and “efficiency” of the bodies (workers, soldiers, citizens) subordinate to the states and their socio-political elites.

The third type is biopower, which is broadly understood power over the human population. Its primary goal is the well-being and size of the population. This power medicalizes and normalizes society and develops the practices of caring for oneself and others. The issue of medicalization came to the fore in the 1970s due to concerns about the growing role of medicine as an area increasingly interfering with people’s everyday lives (Zola 1972). In his early works, Foucault treated medicalization as a practice of power in which the state apparatus, through cooperating doctors, exercises control over various areas of social life in the setting of rules (Foucault 1998). He also presented a history of the progressive medicalization of society from the 19th century onwards. Later, he described biopower as a new kind of power that “relies less on sentencing to death and increasingly so on the right to intervene in one’s way of life, in the

‘how’ of life” (Foucault 2006: 527). Biopower creates safety mechanisms. It can issue a death sentence or allow one to live (2006: 523). This power does not compete with disciplinary power but complements it (Foucault 1998; 2010). According to Foucault, Biopower or biopolitics is the perfect power, as it reaches deeper than previous forms and subordinates its subjects, a power from which comes both the “command to live” and the “consent to death” (Lemke 2010: 44–45). In Foucault’s view, biopower is bipolar. On the one hand, it focuses on the anatomo-politics of the human body, and it seeks to maximize forces and integrate them with efficient systems. At the other end of the spectrum is population biopolitics, which focuses on the control and regulation of processes such as birth, fertility, mortality and longevity (Foucault 2006).

Michael Hardt and Antonio Negri are also concerned with issues of biopolitics. They accuse Foucault of not recognizing and not considering the changes and transformation of biopolitics from modern to postmodern. They focus on the role of capital, labor, and production. They believe that social wealth leads to biopolitical production and the creation of a social life in which the economic, political, and cultural dimensions interpenetrate and enrich each other (Hardt 2005; Hardt – Negri 2004).

Despite the passing of time, Foucault’s concepts of biopower and biopolitics retain considerable analytical utility. Rabinow and Rose (2006) confirm this with their proposal to complement Foucault’s idea. In their opinion, the idea of biopower should include the following elements:

1. One or more truth discourses about the “vital” character of living human beings. These discourses may not only concern biology but could also be hybrid, for example, biological and sociological;

2. The second element is:

“Strategies for intervention upon collective existence in the name of life and health, initially addressed to populations that may or may not be territorialized upon the nation, society, or pre-given communities, but may also be specified in terms of emergent biosocial collectivities, sometimes specified in terms of categories of race, ethnicity, gender or religion, as in the emerging forms of genetic or biological citizenship.” (Rabinow – Rose 2006: 197)

3. The third element includes new ways of empowerment, in which individuals, in the name of concern for their own health and life and that of the entire population, form groups that Rabinow called “biosocieties.” He noted that these new collective social groups revolve around the proliferating categories of bodily vulnerability, somatic suffering, genetic risk, and disease exposure (Rabinow 1996).

## Genetic studies of culturally or geographically isolated groups

Due to the development of genetic technologies, medical procedures now include diagnosis by means of tests, screening, genetic studies and the conceptualization of diseases, not at the cellular level, as before, but at the level of the gene. This has resulted in the “geneticization” of society where, as Abby Lipmann notes, differences between individuals are reduced to their DNA, and most diseases and behaviors are genetically determined (Lippman 1991: 18–19). The development of genetic research has resulted in studies of the gene pools of certain ethnic or national groups, especially culturally or geographically isolated ones. Attention was drawn to the more frequent occurrence of certain genetic diseases in groups that shared a gene pool, such as Ashkenazi Jews from Eastern Europe or African-Americans (Carter 2007: 548). Similarly, Scandinavian communities, especially in Finland, became the subject of genetic research due to low spatial mobility, good genealogical data, and high rates of “inbreeding” (Rose – Novas 2005: 10–11). In Poland, the Kashubians are perceived as a culturally isolated group that has lived on the same territory for centuries. This was due to their distinct language (incomprehensible to Poles and Germans alike), specific customs, extended families residing in one town or nearby, and the conclusion of marriages within a single village

*“Kashubians are considered to be an isolated population since several lines of evidence suggest that they conform to the criteria of such a population: an old settlement, high rates of endogamy with consanguineous marriages between distant relatives, and slow population expansion with negligible immigration accompanied by the conservation of a strong socio-cultural identity, including a distinct dialect and traditional customs.”* (Nedoszytko et al. 2017: 11)

Therefore, Kashubians, especially those living in the northern part of the region, have become “objects of genetic research”. In the age of genetics, genetic research has become ethnic research. By studying gene pools, scientists determine the distinctiveness of individual groups, the influx of foreign genes, the degree of isolation, and more. As early as the 1990s, Alicja Budnik found that Kashubians are genetically different from Poles from other regions of the country and show no similarity to Germans (a group to which Poles attributed the Kashubians in the past, considering them inferior). In another article from 2005, she pointed out that Kashubians living on the Hel Peninsula in particular show high kinship coefficients, which are proof of the extremely high isolation and endogamy on the peninsula both past and present (Budnik

2005: 67). Irena Gałasińska-Pomykoł also dealt with the issue of endogamy in northern Kashubia. She demonstrated that too close kinship resulting from marriages concluded within particular towns and neighborhoods could have contributed to the more frequent occurrence of certain diseases and the deterioration of the population's health condition (Gałasińska-Pomykoł 1965).

### **The Kashubian people**

Kashubians are a group of indigenous Slavic people of Pomerania who have survived in the eastern part of their original territory. According to historians, the territory occupied by Kashubians in the past stretched from Gdańsk in the east, to the Oder river in the west. The first written mention of the people and their name was in a document from 1238 (Labuda 2006: 38). Over the centuries, Kashubians living in Western Pomerania lost their identity succumbing to German assimilation. Catholic Kashubians living in Pomeranian Gdańsk remained separate. After the First World War, most of the areas inhabited by this group fell within the borders of the reborn Polish state. Currently, the population of Kashubians, including people with partial Kashubian lineage, numbers over 560,000 people (Mordawski 2005: 47). They live mainly in the Pomeranian Voivodeship, in Puck, Wejherowo, Kartuzy, and Kościerzyna counties, and parts of Chojnice, Człuchów, Bytów and Lębork counties.

The basis of the identity and distinctiveness of the Kashubians is their culture, especially the Kashubian language. It is the only language in Poland that has regional language status. Some Kashubians believe that they constitute a separate Slavic nation. Apart from their language, Catholicism is an integral element of Kashubian identity. Religion continues to influence many aspects of Kashubian lives, including the number of children in a family. Hence, both in the past and now, the areas inhabited by Kashubians have been characterized by high birth rates compared to other regions of Poland. As in the past, most Kashubians live in the countryside. Consequently, their main occupations are in agriculture, and, in the north of the region, fishing. Some also work in various service-related professions (construction, tourism, car repair). Kashubians are attached to their region and are aware that by living in a compact, relatively homogeneous ethnic group, they will be able to maintain their cultural and linguistic identity.

### **LCHAD enzyme deficiency**

Long-Chain 3-Hydroxyacyl-CoA Dehydrogenase (LCHAD) deficiency is a rare metabolic illness of genetic origin, first identified in 1989. This



disease is rare in Australia and North America but more frequent in Europe, especially in the Baltic Sea region, particularly in countries such as Estonia, Finland (Immonen 2016), and Poland (Piekutowska-Abramczuk et al. 2010).

LCHAD deficiency is an autosomal recessive disease, which means that for a child to be born with it, both parents must be carriers of the mutated gene. It does not manifest any characteristic symptoms, and if not diagnosed in time, it may lead to the sudden death or severe disability of a child (Piekutowska-Abramczuk et al. 2010; Sykut-Cegielska et al. 2011). The disturbance in metabolism is caused by the lack of an enzyme responsible for turning the fat present in one's diet into an energy source. At present, there is no cure for it but it can be treated with an appropriate diet, in which it is essential to replace long-chain fatty acids (butter, olive oil, lard) with complex carbohydrates and medium-chain fatty acids, especially with MCT (medium-chain triglyceride) oil.

In Poland, LCHAD deficiency was first diagnosed in the 1990s. In 2008, tests were carried out on a sample of almost 7,000 children born in various regions of Poland. They showed that the highest number of people affected by this genetic disorder were from the northern part of the Pomeranian Voivodeship, which is inhabited mainly by Kashubians. In this region, the frequency of the mutated gene is 1:73, and in other parts of Poland it is 1:217 (Piekutowska-Abramczuk et al. 2010: 373). Subsequent studies were carried out in the period 2010–2015 on a sample of almost 6,900 people from various regions of Poland, including 1,023 people of Kashubian origin. They confirmed that the highest frequency of the mutant gene responsible for LCHAD deficiency occurs in Pomerania, and in the part inhabited by Kashubians, with a frequency of 1:57. For comparison, the average frequency of the occurrence of this gene in other regions of Poland is 1:163. In Finland the frequency is 1:181 (including in the Bothnia region at 1:132), and in Estonia it is 1:173 (Nedoszytko et al. 2017: 9). Some doctors do not rule out the Kashubian origin of the mutation in the gene responsible for LCHAD deficiency (Piekutowska-Abramczuk et al. 2010: 377; Nedoszytko et al. 2017: 11). On the other hand, geneticists dealing with the problem of the LCHAD deficiency point out that an important role in the genesis of this disease was played by the so-called founder effect. This means that a mutation in a gene was created in one human being, most likely very many years ago, and has been passed on from generation to generation since then. The disease occurs when both parents are carriers of the mutated genes (Gromadzka-Andzelewicz 2009a).

## Control and supervision as an element of biopower

In Foucault's view, one element of biopower is control and supervision. In the era of genetics, this supervision increasingly often relies on genetic tests aimed at early detection of diseases and implementation of treatment. Adele Clarke et al. claim:

*“Genetic susceptibility testing is one of the powerful areas of developing surveillance by identifying individuals and (sub) populations as ‘at risk’. In addition, genetics may define individuals and/or specific (sub) populations as having a varying degree of risk, ranging from ‘low’ to ‘moderate’ and ‘high’ in cases where inherited genetic relatedness or acquired disease susceptibility mutations accumulate.”*  
(Clarke et al. 2009: 24)

After doctors found that a large group of children diagnosed with LCHAD deficiency came from the Pomerania region, a pilot screening of newborns for this disease was launched in 2008. The screening tests revealed that 41 children with a HADHA gene mutation were born in hospitals in the Pomeranian Voivodeship, 39 of which were from areas primarily inhabited by Kashubians. These cases were found in Kartuzy (22), Puck (8), Kościerzyna (6), Chojnice (2) and Wejherowo (1) (Piekutowska-Abramczuk et al. 2010: 375). From October 2010, pilot screening tests for children were introduced in the Pomeranian Voivodeship. The research was carried out with the consent of the children's parents. As far as I am aware, there were no cases where Kashubian parents refused permission to test their children, although doctors were initially afraid that might happen. Since 2015, these screening tests have been included in the compulsory screening tests for all newborns in Poland, which are financed by the Ministry of Health. It was Pomeranian doctors who lobbied for the inclusion, with the justification that if this disease remains undiagnosed in the first months of a child's life, it may cause disability or death. This confirms what Foucault described when biopower is manifested in the right to intervene to preserve the life of individuals (Foucault 2006: 527). In this case, the intervention consisted of testing the blood of newborn babies to detect changes in the gene responsible for the disease. Diagnosing the disease at an early stage results in treatment, the primary component of which is a special diet. Its use is associated with discipline and control of the patient. It is also part of the biopower, which aims to “produce” efficient individuals.

Therefore, in this described case, biopower is combined with disciplinary power (Dreyfus – Rabinow 1983). Hence, detecting a damaged gene in

a child means that its siblings and possibly other young relatives are referred for tests. Thus, the supervision and control covers a wider group of persons associated with the risk group. It aims to detect people who are carriers of the mutated gene responsible for the disease. The knowledge available from genetic testing contributes to the elimination of uncertainty, but at the same time, it also generates problems. One is the concern among the inhabitants of the region regarding the issue of their adolescent children choosing partners. One interviewee said, “*when people didn’t know about this gene, they didn’t worry about this disease, and now there is some anxiety*” (W-12, F/40).<sup>2</sup> This concern stems from the fact that Kashubians living in the same town for decades or even centuries are related to each other to varying degrees. One interviewee described it as follows:

*“Here in S., and in Kashubia in general, many families inter-married with their neighbors, and basically half the village is related. And then, if there are any such defects, they accumulate and hence the disease appears.”* (W-18, F/58)

Another interviewee said:

*“That’s why I say it results from kinship, this disease was somehow dormant here [...] I acted deliberately, to a great extent, when I got married, in that I took a wife from the East. I think it worked out well.”* (W-8, M/70).

This demonstrates that biopower can change the view and judgements of the Kashubian community with regard to its cultural practices. Customs that were popular in the past are being questioned, while those that were not well regarded (marriages to “foreigners”, particularly other national groups) have unexpectedly had a positive outcome.

Foucault points out that, due to the proliferation of subtle power-knowledge networks, health is no longer the private affair of the individual. Modern medicine and genetics are interested not only in disease as such, but the risk of its occurrence. Doctors’ knowledge of the risks becomes a source of power and control over individuals or groups. He writes “*power and knowledge directly imply one another; there is no power relation without the correlative constitution of a field of knowledge, nor any knowledge that does not presuppose and constitute at the same time power relations*” (Foucault 1998: 29).

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2 W-12, F/40: W-12 – interview number; F/M – woman/man, gender of the interlocutor; 40 – age of the interlocutor.

Doctors inform people who have been diagnosed with a defective gene that if both parents are carriers, the risk of developing LCHAD deficiency is 25%, and half of their offspring, according to the pattern of inheritance of autosomal recessive genes, are healthy carriers of the mutated gene. Information about a diagnosed genetic disease of a child may come as a shock to the parents.

*“When you look at the percentages, it’s not a lot, but when it comes to genes, it is. This is not enough, the 25 percent [...] For me, it was such a great shock that my child fell ill and has this disease. We spoke with my mother and mother-in-law to find out whether any children had died, and yes there were some, but we don’t know what caused it. Both in my family and on my husband’s side two kids did die, but we don’t know what caused it.” (W-11, F/approx. 42)*

In families that have had a case of the illness, doctors recommend that all young people undergo the tests, although the National Health Fund only finances testing for the immediate family. In other cases, the decision and costs are the private concern of people who decide to be tested. Even so, doctors are interested in their results. One interviewee who had a family member diagnosed with LCHAD deficiency referred to tests for young people with the following remarks:

*“[...] what they will do, we’ll never know. Will they want to get tested or not? Well, I think that they could be tested, yes. But maybe everyone has to grow up on their own and will think for themselves, yes, listen, maybe we’ll get a better test, maybe let’s do it, we’ll know, yes. You know, I have an ill person in my immediate family and it could always be a [defective gene]. But I don’t know, I don’t know what they will do.” (W-11, F/approx. 42)*

Private laboratories in Poland have started offering genetic tests to detect changes in the HADHA gene responsible for the deficiency. Some have begun to publish information leaflets that state that the mutation in the gene often occurs in Kashubia, thus suggesting that people from this region in particular should be tested. This demonstrates that biopower has increased surveillance and control capabilities while reducing the costs of public health care. The costs are borne by those who, fearing for their health and that of their children, perform tests at their own expense. They take responsibility for their own health, which is one of the manifestations of biopower (Nye 2003).

Knowledge of how genes are inherited and the prevalence of genetic diseases, in addition to occupational dominance, can lead to a false sense of objectivity and confidence in the medical profession (Wolinsky 1988: 37). In the case described above, some doctors concluded that they were sufficiently competent to disseminate the unproven thesis that the reasons for the relatively frequent occurrence of the disease among Kashubians were their cultural and geographical isolation, the lack of interaction outsiders and therefore also a deficit of new genes:

*“We know that in populations that have grown from a small number of founders and have kept a separate identity, for either geographical, religious, or other reasons, individual genetic disorders may be unusually more common than in more mixed populations. This situation can be observed in the Pomeranian region of Poland, which is partly inhabited by an ancient Kashubian population.”* (Piekutowska-Abramczuk et al. 2010: 376)

The issue of the relatively frequent occurrence of LCHAD deficiency in the Kashubian population quickly caught the attention of the media, as both genetic diseases and problems related to isolated communities are attractive and popular topics for them.

### **Doctors, the media, and the construction of an ethnic illness**

For over two decades, researchers studying media’s role in the transfer and dissemination of scientific knowledge in society, including genetics, have pointed to the media’s growing role in this realm (Conrad 1999; Nelkin – Lindee 1999; Domaradzki 2017), and also a kind of “excessive hype around genetics” (Bubela – Caulfield 2004; Petersen 2001). The media have a key influence on the selection and problematization of the genetics-related topics they present. The hype surrounding genetics and a certain kind of media fever are also often created by scientists themselves (Domaradzki 2017: 131). The presence of scientists in the media is a form of self-promotion, as it can increase their profile in the scientific community, while demonstrating the practical application of their research may facilitate the acquisition of further research grants. The media hype surrounding genetics is also created by scientific journals that prioritize information and publications on new discoveries and the relationship between genetics and disease. The biotechnology industry, politicians, and public opinion play an important role in the discourse on genetics (Domaradzki 2017: 132). Biotech companies can use the media and scientists as channels to

promote their services. In turn, politicians may regard genetic technology as the best form of disease prevention (Lippman 1991). Because topics related to genetics are of public interest, journalists may raise certain issues to attract their readers' attention. Although the media play an important role in disseminating information related to genetics and shaping public opinion, there are more complex relationships between science, media, and society (Domaradzki 2017).

Publications and statements for the media issued by medical researchers on LCHAD deficiency in the Kashubian population and their cultural interpretations of the relatively high frequency of the disease in this group resulted in over 30 regional and national press and internet articles on this issue between 2008 and 2017. An analysis of the discourse in these articles reveals the role doctors and journalists played in construing this as an ethnic Kashubian disease. According to Małgorzata Lisowska-Magdziarz, media discourse is “*a set of ways of deliberate, non-accidental use of language to communicate information, opinions, values, concepts, and views of the media on different topics*” (2001: 8). Its participants, through statements, can create, confirm, but also question established cultural rules, and build or overthrow stereotypes regarding, for example, ethnic, religious or national groups.

This discourse focused on the following issues: 1) Death of a child with LCHAD enzyme deficiency and the search for those responsible; 2) Symptoms of the disease, and methods of diagnosis and treatment; 3) Reasons for its relatively high incidence in the Kashubian population; 4) Ethnic diseases; and 5) The need for screening tests for Kashubian children. The discourse was initiated by two articles that appeared on 7 March 2008 in the local *Tygodnik Kartuzy* weekly. They concerned a tragic local event, which was the death of a six-month-old boy sent away from a hospital emergency room in Kartuzy for procedural reasons (the child's mother did not have a doctor's referral from her place of residence).

After the case was publicized in the media, in determining the cause of death, it turned out that the child had suffered from a previously undiagnosed LCHAD deficiency. In describing this tragic event, the journalists initially presented a picture of the public demanding the punishment of those who had refused to admit the child to hospital. The narrative in the following article was quite different; the same journalists – Emila Leman and Jolanta Stefanowska – began to draw attention to the stressful nature of doctors' work and that of the whole health service, as well as the entitlement of certain patients (Leman – Stefanowska 2008). In the article, they presented the perspective of the field of power that the whole of the health care system occupies. The same is true of the interview with the president of the Private Healthcare Complex in Kartuzy, who was the superior of

the doctor who had refused to admit the child to the hospital. Using the field of institutional power and medical knowledge, he defended the doctor, even though, from the perspective of public opinion, her conduct was inconsistent with the rules applicable to doctors. The public, whose view was reflected by journalists, was outraged by the fact that the doctor had only examined the child very superficially and sent him for a referral, without admitting him for observation. This shows the changing role of patients, who disagree with the authoritarian approach of doctors, criticize their decisions, and increasingly refer cases of medical malpractice to the courts.

As mentioned above, according to Foucault, contemporary biopower does not mean that doctors exercise direct strict control and supervision over society, as was the case in the era of disciplinary authority. It manifests itself in the penetration of medical discourse into the collective consciousness. The discourse on LCHAD deficiency in the Kashubian population is a case in point. On the one hand, the authors of press and online articles presented medical data obtained from doctors. On the other, they expanded the socio-cultural threads related to the causes of the disease. In taking advantage of the power of the media, journalists and doctors, they contributed to the popularization of the term “Kashubian gene”, and thus the creation of LCHAD deficiency as a Kashubian ethnic disease.

An article by Alicja Katarzyńska entitled “The Curse of the Kashubians” published in the nationwide opinion-forming daily *Gazeta Wyborcza* (19.03.2008) played an important role in this process. In the first part of the article, the author cited information obtained from Dr. Jolanta Wierzba from the Academic Clinical Center in Gdańsk, who talked about the symptoms of the disease. She also stated that, in the opinion of another doctor, Dr Dorota Piekutowska-Abramczuk from the Children’s Memorial Health Institute in Warsaw, the reason for the relatively frequent occurrence of this disease among Kashubians is the fact that “they live in a small, closed population within which they reproduce”. One of the article’s subheadings, entitled “Fresh blood is needed,” suggests that Kashubians should seek partners outside their ethnic-regional group so as to have healthy offspring. This is an example of how medicine, through its moral privileges stemming from its mission to protect human life and health, tries to influence and transform interpersonal relations. In this case, it targets the marital customs and image of this ethnic-regional group. The Kashubians are presented as a closed group with outdated traditions and cultural practices that deviate from contemporary norms.

The ethnicization of the disease came about through articles on LCHAD deficiency in the Kashubian population, in which the term “Kashubian gene” was used, thereby linking the condition to the ethnic group. For

example, Jolanta Gromadzka Andzelewicz in the article “The Kashubian gene killed Dawidek,” wrote:

*“Research carried out at the Children’s Memorial Health Institute in Warsaw showed that the boy suffered from a deadly disease, LCHAD deficiency. This is caused by a damaged gene, commonly known as the Kashubian gene, because most of its carriers live around Kartuzy, Kościerzyna, and Żukowo.”* (Gromadzka-Andzelewicz 2009b)

The author does not mention the fact that it is a relatively rare disease. Therefore, the reader may later recall that many Kashubians are carriers of the mutated gene. On the other hand, in the article “The Gene that a Swede Left for the Kashubians”, LCHAD deficiency was very clearly presented as an ethnic disease by associating it with diseases that are prevalent among certain religious and national groups:

*“Among the Amish living in the Cape Cod region of South Africa, porphyria, which is an extremely rare genetic blood disease that makes a person look like a vampire, is very common [...] Indians have their disease - thalassemia (a type of anemia), Blacks or African-Americans – sickle cell anemia, and the Finns – the so-called Finnish nephrotic syndrome (kidney disease).”* (Gromadzka-Andzelewicz 2009b)

Moreover, in the article entitled “The Dangerous Kashubian Gene” Stefania Najsarek emphasized that gene mutations occur in closed communities and that Kashubians are such a community:

*“Kashubians, strongly attached to their traditions and culture, choose life partners from within their own community. Relationships between people who have been related for generations, lacking an inflow of “fresh blood” from people from outside the ethnic group, expose populations to more frequent occurrences of genetically determined disorders.”* (Najsarek 2009)

The article “What is the Kashubian Gene?” published on *Nadmorski.pl* (Czym jest gen kaszubski? 2010), features an interview with a doctor who explains the nature of the disease, but does not distance herself from the term “Kashubian gene.” Contrary to what some of her colleagues claim, she says: “Doctors are not yet able to answer the question of why LCHAD deficiency specifically is so frequent in Kashubia.” At the end of another article, “Does the Kashubian Gene Kill?” the author states: “It would be ideal to continue the



*program and systematically test newborns for the presence of this dangerous gene, and for future mothers who have been identified as having the defective gene to have guaranteed access to prenatal diagnostics.”* (Kaszubski gen 2010) Information about the lack of funding for screening also appears in several other articles. This indicates that journalists and doctors treat publications in the media as a way of informing the public about the disease and its socio-cultural causes and also as a method of exerting pressure on the authorities to fund further research.

For the medical researchers whose statements are quoted, by demonstrating the need for and the importance of the research they carry out, they can also increase the likelihood of receiving further research grants (Domaradzki 2017) (research in 2008 was financed by a grant awarded by the Scientific Research Committee, which was the main body awarding scientific research grants in Poland at the time). One geneticist was quoted in the press saying that his institute could conduct tests on Kashubian newborns to search for the defective gene:

*“In the case of the gene commonly known as Kashubian, the matter is much simpler. The mutation has been known for many years. The cost of examining a child is low, less than one hundred Polish zlotys. The Department of Genetic Biology at the Medical University of Gdańsk, led by Professor [Janusz] Limon, would like to study Kashubian newborns. Together with Dr. Jolanta Wierzba, in cooperation with the Voivodeship pediatrics consultant, Professor Limon wants to apply to the branch of the National Health Fund (NFZ) in Gdańsk with a request for finance for this research.”* (Gromadzka-Andzelewicz 2009)

As a result of doctors’ statements that were popularized and publicized in a series of articles in the press and on the Internet, in leaflets in hospitals and in special educational campaigns, the term “Kashubian gene” has become a colloquial term for LCHAD deficiency. This illustrates how symbolic violence is connected with the dissemination of knowledge about genetic diseases. According to Bourdieu, this violence is a tool for constructing social reality. It is part of a discourse that is not symmetrical and objective but is an element of domination (Bourdieu – Wacquant 2001: 137). This domination is connected with the symbolic elite’s access to legitimate channels of information distribution. Wielding their cultural capital, journalists selected the content they wanted to publish, and at the same time, attracted the attention of their readership with sensational titles and content. In the

effort to attract readers, they presented the disease as almost endemic in the Kashubian population by comparing it to diseases occurring in endogamous religious groups, racial or national groups. Above all, they popularized the non-medical, ethnic definition of the disease and thus created the concept of a Kashubian disease. In media coverage, the “Kashubian gene” was presented as a near-endemic disease of this group that has been culturally conditioned. This name is now used less frequently in official publications, after being criticized by ethnic Kashubian activists, who consider it stigmatizing. However, it is still used colloquially.

In this case of creating an ethnic disease, an important role was played by doctors, whose professional status related to biopower gave them the confidence to consider themselves competent to express their opinions on non-medical issues. Freidson even considered doctors to be “moral entrepreneurs” participating in the social construction of disease (Freidson 1970: 244–301). In the examined case, this construction is related to genetics, which strips humans down to their genes, facilitates their medicalization, and allows some diseases to become “ethnic”.

The ethnic labeling of the term “Kashubian gene” received criticism from the Kashubian community. In the course of my research, community representatives expressed fears that this colloquial term may cause all Kashubians to be perceived as potential carriers of the mutated gene. *“This name [the Kashubian gene] suggests that many of us, Kashubians, or all of us, carry this gene, which is not true.”* (W-24, F/30) Some of the interviewees indicated the stigmatizing nature of the name (W-14, M/c.45; W-11, F/c.40).

Apart from the adverse effect of propagating the ethnic label “Kashubian gene”, biopower has also had certain positive effects. The publicizing of the issue of LCHAD deficiency in the Kashubian population has led to the screening of newborns in the region of Pomerania. Since 2015, these tests have been included in the package of free, standard, mandatory tests for newborns carried out throughout Poland. Thus, diseases can be promptly diagnosed and treated, and lives can often be saved. This is how biopower “commands one to live”. Nevertheless, it should be noted that the public health program Newborn Screening Program in Poland for 2019–2022, which was published by the Ministry of Health, includes the following entry: *“LCHAD deficiency – the average frequency of occurrence in Poland is around 1:118,000 births, and in the Kashubian region approximately 1:17,000”* (Minister Zdrowia 2018: 19). Such information, although seemingly purely medical, to some extent legitimizes and strengthens the ethnic character of the disease.

## Biopower and ethnic issues

In the era of biopower, medicine uses various modern technologies, one of which is genetic research. It has contributed to the discovery of new diseases and also to the study of the gene pools of different populations. This has led to genetic research becoming ethnic research, where ethnic groups can be distinguished through genes and genetic genealogies. In the studies mentioned above, Alicja Budnik demonstrated that Kashubians differ genetically from Germans, thus contradicting the stereotype that Kashubians are closely related to Germans on account of centuries of geographical proximity.

*“The analysis of genetic distances between Kashubians, other Poles, and the population of other Baltic countries, as well as the values of inter-population kinship coefficients – no matter how they are estimated – place both Kashubian groups among the Balto-Slavic and Uralic countries, clearly distinguishing them from Germanic countries. Intensive and long-term attempts to Germanize the Kashubians left no trace on the genetic markers examined in the research.”*  
(Budnik 1996: 41)

Biopower may also contribute to the reinstatement of ethnic stereotypes. In the examined case, the ethnic label for the disease and cultural interpretation of its causes became part of the negative stereotype of Kashubians. Thus, biopower revived old problems related to the perception of Kashubians by Poles from other regions as a closed, culturally backward group, which engages in incest and endogamy. In the analyzed discourse, these issues were revealed especially in the comments made by Internet users under articles on the “Kashubian gene”.

*“The Kashubian gene? Perhaps the people from the above-mentioned areas should be examined in terms of reproductive mating between cousins, fathers and daughters, and siblings. These are frequent gene combinations that affect later generations [...] There should be a very restrictive law in this country that would not allow partnerships even within the extended family. Nobody abides by this. The worst thing is that everyone pretends that nothing is happening, but it does happen. Kashubians are very closed, distrustful, backward people, they aren't open toward strangers, hence the problem.”* (Wykrycie 2010, obserwator, 11/10/2010)

Another netizen wrote:

*“The Kashubian gene... and that is why there are so many handicapped people in Pomerania. The largest psychiatric hospital in Europe had to be built by the Germans in Starogard Gdański [...] Kashubians are very religious, God-fearing people and they always do everything according to God’s rule and by the commandments. Another factor could also be the widespread drunkenness in Pomerania over the centuries, where in an average village one or several rich German bumpkins lived, one Jew always had an inn where the peasantry got drunk and the rest were simple and usually very ignorant, superstitious Kashubians.”* (Wykrycie 2010, Ambasada Prusaków 8/10/2010)

The cultural interpretation of the occurrence of LCHAD deficiency in the Kashubian population partly contributed to undermining the positive self-image of Kashubians. The medical community undermined the pride associated with Kashubian endurance, the tradition of extended families living in local villages for over 150 years.

This shows that biopower affects intergroup relations, changes the image of ethnic groups, and causes changes in the collective identity. However, neither individuals nor ethnic groups remain passive in the face of biopower. The ethnically labeling nature of the term “Kashubian gene” has been criticized by the Kashubian community, which does not want the term to become a part of their group identity. In the course of my research, they indicated that this term might cause all Kashubians to be perceived as potential carriers of the mutated gene.

In many statements, community leaders and ordinary Kashubians pointed out that the term “Kashubian gene” is stigmatizing and should not be used:

*“The very term ‘Kashubian gene’ is already so stigmatizing. It means that Kashubians carry something that is a potential threat and that it is better not to associate with Kashubians.”* (W-14, M/approx. 45)

Bogusław Nedoszytko, a doctor from Kashubia, wrote that the mutated gene:

*“[...] was probably introduced into the Kashubian population from Scandinavia. Therefore, it should rather be called, for example, a ‘mutation typical of inhabitants of the Baltic coast’. Using the term ‘Kashubian gene’ denigrates, stigmatizes, and its use should be discontinued.”* (2018:7)

As a result, the term “Kashubian gene” is now less common in articles and information leaflets, which shows that Kashubians have been able to defend themselves and fight against the ethnic label.

*“Another strategy Kashubians use is to ridicule and downplay the newspapers in which the articles were published, calling them ‘untrustworthy newspapers’ and saying that ‘journalists just need something to write about.’ Some interlocutors questioned the opinions of doctors that endogamy is the cause behind the frequent occurrence of the disease and that therefore one should look for partners from outside one’s ethnic group.” (W-8, M/70).*

## Conclusion

Biopower is broadly defined power over a population. It includes interventions in collective existence in the name of the life and health of ethnic groups or entire nations (Rabinow – Rose 2006: 197). These interventions are aimed at optimizing groups by improving birth rates, reducing deaths and limiting the spread of diseases. They result from a concern for the health of the population with regard to making it more efficient, for example, at work or in other areas of social life.

Biopower has caused the role of medicine and doctors to change: they are now not merely officials in the service of the state, but rather experts in medical discourse. This discourse includes the appropriate language, the position and role of the doctor and the patient, the relationships and distances between them, and also the networks of institutions such as hospitals, laboratories and clinics. This discourse forms social practices and relevant knowledge. At the core of these discursive practices are relationships of domination and submission that medicalize society and ‘create’ diseases. The domination is related to the specific nature of the medical profession, which has a high degree of autonomy resulting from knowledge, asymmetric doctor-patient relations, and the social position of doctors. This allows them to medicalize society and create new diseases. In this case study, the doctors and collaborating journalists turned a rare genetic disease into an ethnic disease by labeling it the “Kashubian gene”. The name suggests that the disease is common in this ethnic-regional group. In this creation of an ethnic disease, symbolic violence and knowledge-power relations are visible. This (bio) power and professional domination of physicians can lead to a false sense of confidence. In the case of the Kashubians, doctors went beyond the scope of medicine in seeking historical and cultural explana-

tions for the higher prevalence of LCHAD deficiency in this group. As a result, they disseminated an unproven hypothesis attributing the higher prevalence of the illness in the Kashubian population compared to other regions to a lack of mobility, endogamy, and a deficit of “fresh blood” in the community. This caused resentment among Kashubians.

In Foucault’s theory, biopower is not negative repression, as it also can have positive effects (2000: 217). It does so through a strategy of intervention in collective existence (Rose – Novas 2006). In this case study, this involved the inclusion of LCHAD deficiency in compulsory, free screening tests for newborns in Poland since 2015. This has contributed to saving human lives and protecting them from disability. Through mandatory interventions, biopower shapes the life and health of the population.

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