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Case Report

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Hereditary Conditions and Reproductive Coercion: Letter from Russia

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Abstract

An individual feels ashamed when some undesirable truth about one's fundamental character is revealed to the self or others. Sick and unattractive people often appear as sufferers of shame [1]. Besides, whistle-blowing and denunciation are often regarded as shameful acts. On the contrary, many violators of laws and mores do not experience any shame and emerge as winners. This pertains to diverse phenomena, discussed in preceding publications: child and elder abuse, sexual coercion, professional misconduct in medicine. For doctors, this applies to suboptimal prescriptions due to conflicts of interest, let alone invasive procedures without sufficient indications [2,3]. What can be done to route the emotion of shame in the right direction, so that not the victims and whistleblowers but the perpetrators would be ashamed? Publications with names and references seem to be the best way.

In a milieu tolerating sexual and reproductive coercion, where sexually transmitted infections (STI) or hereditary diseases are concealed from partners, such conditions cease to be a private matter. In case of the latter, this pertains also to the kinship. Contraceptive sabotage should be regarded as offence with infliction of bodily harm if an abortion or unwanted pregnancy, STI or genetic disease has been inflicted. In particular, concealment from a partner or spouse of a known hereditary disorder may have grave consequences. Of note, STI are usually curable but genetic diseases are generally not. This gives to a medical professional a moral right in some cases to disregard the obligation to secrecy, when it can be assumed that of the offender, his or her relatives would continue spreading abnormal genotype. Fortunately, genetic testing and counseling are improving; so that the above considerations may be revised one day.

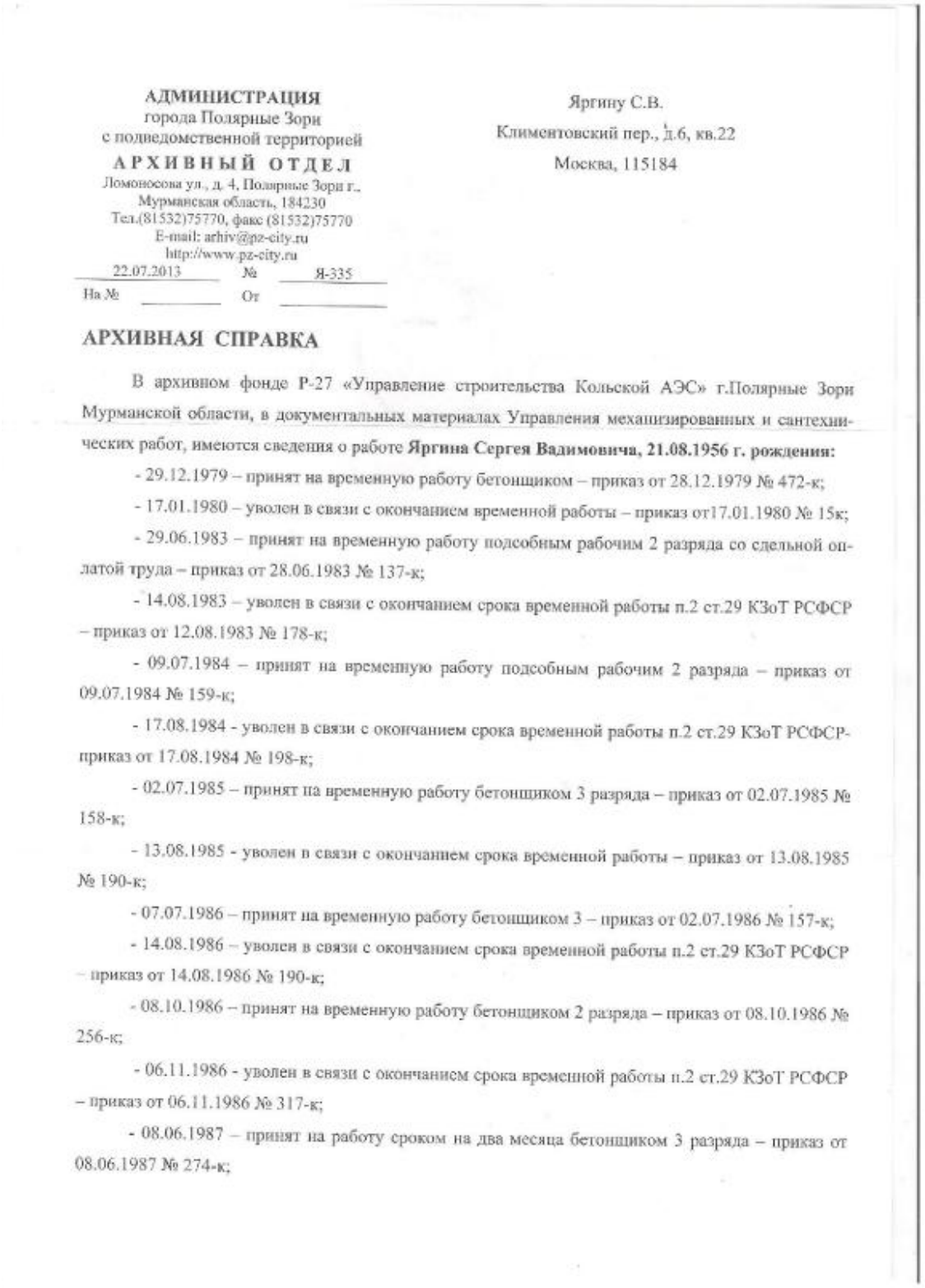
1. Case Report

Marfan syndrome (MS) is a disorder with weakness of connective tissue, inherited according to the autosomal dominant pattern, having variable penetrance. There is abundant literature about MS; and the symptoms are generally known. This case report illustrates late consequences of lifting heavy weights by an individual with belated diagnosis of moderately expressed MS. The patients are discouraged from heavy weightlifting, contact sports (rugby, boxing), high G-force activities and deep-sea diving. However, most of them may engage in athletic and other physical activities with moderate load. At the same time, it was noticed that there is little real-world data to support the lifestyle recommendations [4].

The family history of S. illustrated the psychological mechanism "like will to like", which can facilitate marriages between individuals with related hereditary conditions. Other people would perceive an abnormality, but a person somewhat similar to oneself might provoke interest and sympathy. This is potentially dangerous for the offspring. Both his parents were ethnic Russians. The mother had moderately expressed marfanoid appearance. The father was tall with the head circumference ~61 cm, otherwise nondescript. However, the father's sister and daughter from his first marriage both had marfanoid body structure. Moderately expressed symptoms of MS are recognizable in S.: tall stature, thin skeleton with lax joints, moderate arachnodactyly, pes planus and slight kyphosis diagnosed in childhood. From adolescence on, S. heard comments about his "feebleness" and overcompensated this by some sports: rowing, backpacker tourism, fitness training including weightlifting. Starting at the age of 18 years, he repeatedly participated in construction and forestry works during holydays,

totaled to 3 years plus more than 2 years of army service. These activities included lifting of heavy weights. Marfan syndrome was not diagnosed at yearly checkups (dispensarizations) neither at the Sechenov Medical Academy, where S. studied and was employed in the period 1973-1990, nor at other institutions. Hereditary diseases have not been given sufficient attention at the above-named Academy. The diagnosis was suspected at the age over 30 years, when S. already had visible asymmetry of the inguinal region. At the age of 66 years, along with atrophy of abdominal muscles, S. developed prolapse of his lower abdominal wall (Figure 1) and descensus perinei with foot edema predominantly on left side; more images are in the article by Jargin (2025) [5]. He can sleep only keeping his lower limbs apart e.g. with a balloon ~40 cm in diameter between his thighs, otherwise circulation disturbances in the limbs become perceptible due to perineal descent with compression of blood vessels. Besides, he has a hiatal hernia and radiologically confirmed old compressive fracture of the C6 vertebral body with recurrent pains and symptoms of vertebrobasilar insufficiency. Emergence of the fracture coincided with heavy weight lifting during construction works at the age of 29 years (8-2,3) [6].

Figure 1: Patient S. 69 Years Old With Marfanoid Body Structure. Prolapse of Abdominal Wall as a Result of Heavy Weight Lifting



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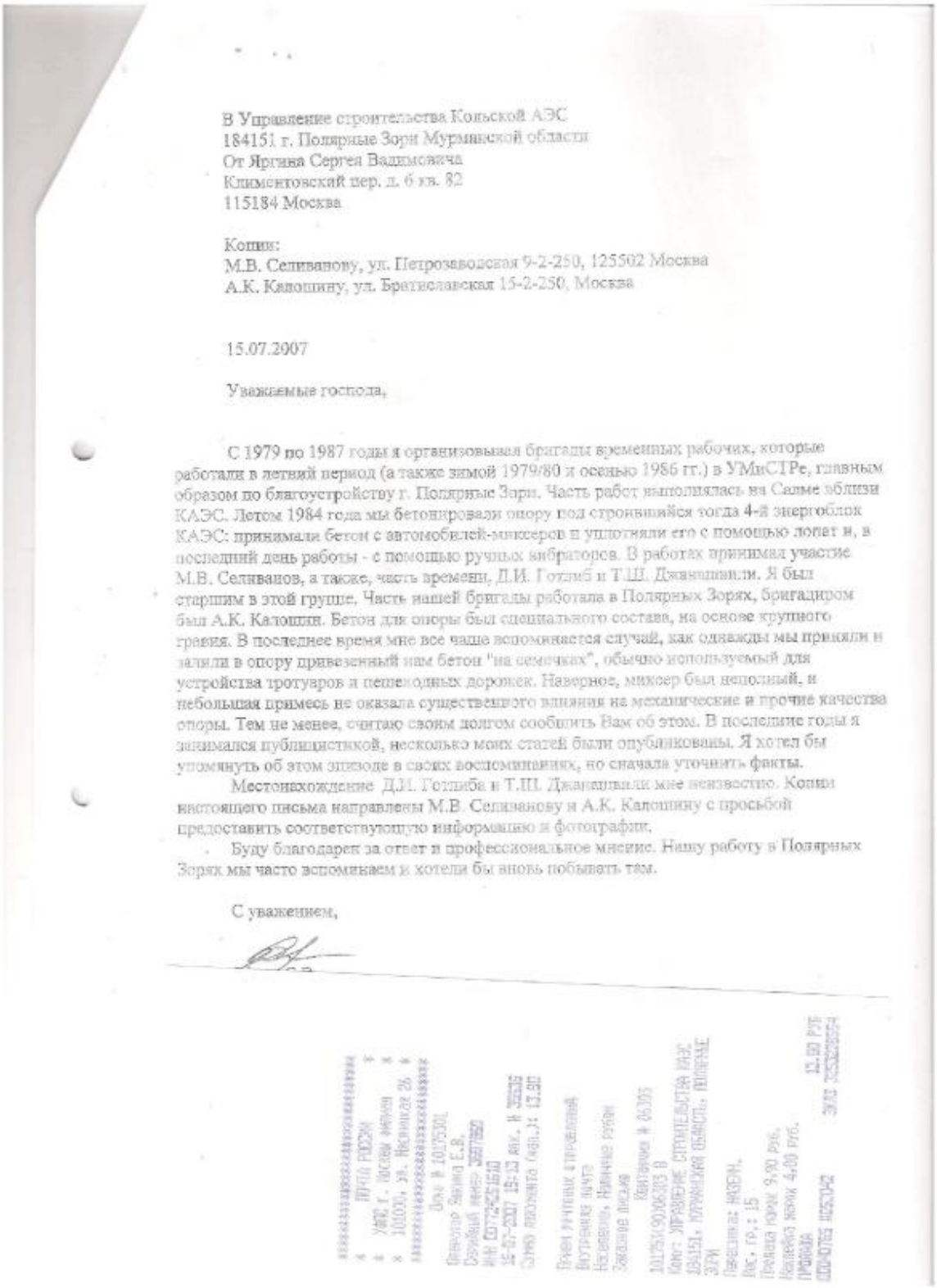
АРХИВНАЯ СПРАВКА

В архивном фонде Р-27 «Управление строительства Кольской АЭС» г.Полярные Зори Мурманской области, в документальных материалах Управления механизированных и сантехнических работ, имеются сведения о работе **Яргина Сергея Вадимовича, 21.08.1956 г. рождения:**

- 29.12.1979 – принят на временную работу бетонщиком – приказ от 28.12.1979 № 472-к;
- 17.01.1980 – уволен в связи с окончанием временной работы – приказ от17.01.1980 № 15к;
- 29.06.1983 – принят на временную работу подсобным рабочим 2 разряда со сдельной оплатой труда – приказ от 28.06.1983 № 137-к;
- 14.08.1983 – уволен в связи с окончанием срока временной работы п.2 ст.29 КЗоТ РСФСР – приказ от 12.08.1983 № 178-к;
- 09.07.1984 – принят на временную работу подсобным рабочим 2 разряда – приказ от 09.07.1984 № 159-к;
- 17.08.1984 - уволен в связи с окончанием срока временной работы п.2 ст.29 КЗоТ РСФСР- приказ от 17.08.1984 № 198-к;
- 02.07.1985 – принят па временную работу бетонщиком 3 разряда – приказ от 02.07.1985 № 158-к;
- 13.08.1985 - уволен в связи с окончанием срока временной работы – приказ от 13.08.1985 № 190-к;
- 07.07.1986 – принят на временную работу бетонщиком 3 – приказ от 02.07.1986 № 157-к;
- 14.08.1986 – уволен в связи с окончанием срока временной работы п.2 ст.29 КЗоТ РСФСР – приказ от 14.08.1986 № 190-к;
- 08.10.1986 – принят на временную работу бетонщиком 2 разряда – приказ от 08.10.1986 № 256-к;
- 06.11.1986 - уволен в связи с окончанием срока временной работы п.2 ст.29 КЗоТ РСФСР – приказ от 06.11.1986 № 317-к;
- 08.06.1987 – принят на работу сроком на два месяца бетонщиком 3 разряда – приказ от 08.06.1987 № 274-к;

Figure 2: Certificate Confirming Repeated Temporary Employment with the Construction Management of the Kola Nuclear Power Plant. The Dates can be Seen. The Factual Working Time was Longer Than Indicated on the Certificate



В Управление строительства Кольской АЭС
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15.07.2007

Уважаемые господа,

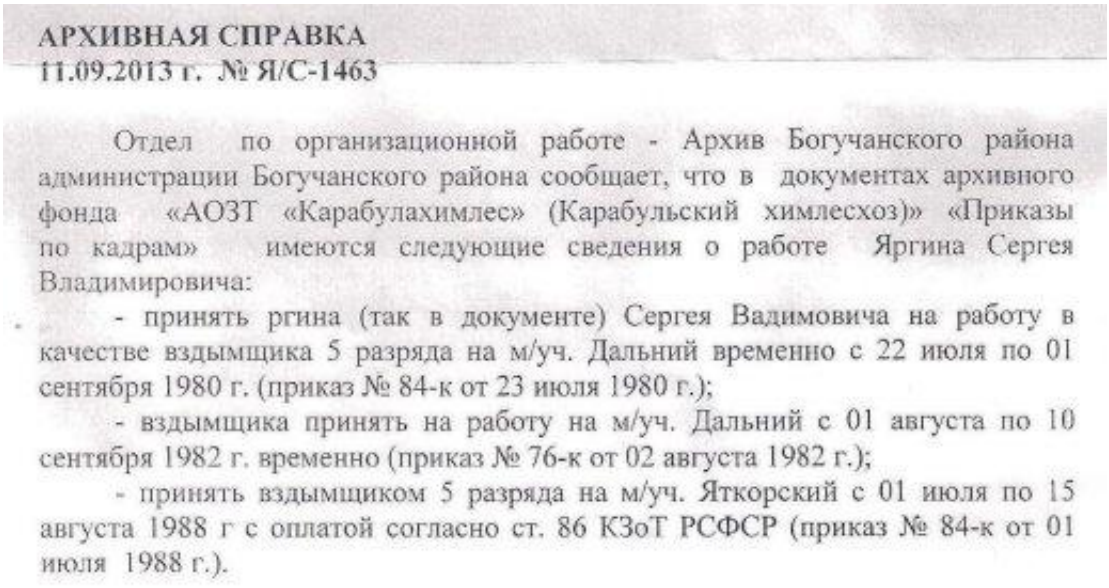
С 1979 по 1987 годы я организовывал бригады временных рабочих, которые работали в летний период (а также зимой 1979/80 и осенью 1986 гг.) в УМиСТРе, главным образом по благоустройству г. Полярные Зори. Часть работ выполнялась на Салме вблизи КАЭС. Летом 1984 года мы бетонировали опору под строившийся тогда 4-й энергоблок КАЭС: принимали бетон с автомобилей-миксеров и уплотняли его с помощью лопат и, в последний день работы - с помощью ручных вибраторов. В работах принимал участие М.В. Селиванов, а также, часть времени, Л.И. Готлиб и Т.Ш. Джанашвили. Я был старшим в этой группе. Часть нашей бригады работала в Полярных Зорях, бригадиром был А.К. Калошин. Бетон для опоры был специального состава, на основе крупного гравия. В последнее время мне все чаще вспоминается случай, как однажды мы приняли и залили в опору привезенный нам бетон "на семечках", обычно используемый для устройства тротуаров и пешеходных дорожек. Наверное, миксер был неполный, и небольшая примесь не оказала существенного влияния на механические и прочие качества опоры. Тем не менее, считаю своим долгом сообщить Вам об этом. В последние годы я занимался публицистикой, несколько моих статей были опубликованы. Я хотел бы упомянуть об этом эпизоде в своих воспоминаниях, но сначала уточнить факты.

Местонахождение Л.И. Готлиба и Т.Ш. Джанашвили мне неизвестно. Копии настоящего письма направлены М.В. Селиванову и А.К. Калошину с просьбой предоставить соответствующую информацию и фотографии.

Буду благодарен за ответ и профессиональное мнение. Нашу работу в Полярных Зорях мы часто вспоминаем и хотели бы вновь побывать там.

С уважением,

Figure 3: A Report to the Construction Management of the Kola Nuclear Power Plant on Inadequate Quality of Concrete Used for the Foundation of the Reactor No. 4



АРХИВНАЯ СПРАВКА
11.09.2013 г. № Я/С-1463

Отдел по организационной работе - Архив Богучанского района администрации Богучанского района сообщает, что в документах архивного фонда «АОЗТ «Карабулахимлес» (Карабульский химлесхоз)» «Приказы по кадрам» имеются следующие сведения о работе Яргина Сергея Владимировича:

- принять ргина (так в документе) Сергея Вадимовича на работу в качестве вздымщика 5 разряда на м/уч. Дальний временно с 22 июля по 01 сентября 1980 г. (приказ № 84-к от 23 июля 1980 г.);
- вздымщика принять на работу на м/уч. Дальний с 01 августа по 10 сентября 1982 г. временно (приказ № 76-к от 02 августа 1982 г.);
- принять вздымщиком 5 разряда на м/уч. Яткорский с 01 июля по 15 августа 1988 г с оплатой согласно ст. 86 КЗоТ РСФСР (приказ № 84-к от 01 июля 1988 г.).

Figure 4: Certificate Confirming Works in Pine Tree Tapping in Siberia. The Factual Working Time was Longer than Indicated on the Certificate

The vertebral injury mentioned above should be further commented. In the period 1979-1987, S. participated in construction of the Kola Nuclear Power Plant and the nearby town Polyarnye Zori (Polar Dawns) (Figures 2,3). In 1984 and 1985 S. he participated in works, where concrete had to be carried by barrows. They worked on average 16 hours a day without holidays, making concrete works and doing other tasks. The vertebral column sent feedback through afferent channels: he should not carry heavy weights. The barrow became heavier, and the pain in the spine got worse. It started to hurt again 12 years later, in the cervical area, when S. practiced abroad as a pathologist and started to go on long-distance bicycle trips to counteract the sedentary lifestyle. At first, it was difficult to turn his head changing traffic lanes; the pain later became almost permanent, forcing him to get off the bicycle and walk. The conclusion, after radiography, was: old compressive fracture of the C6 vertebral body. S. had to avoid any load on the shoulder girdle. The barrow was overloaded by the temporary team-leader Dmitri Gotlib. S. has a visibly thin skeleton; the barrow was too heavy for him, but he had difficulties with saying "No"; and surrounding persons knew this. Gotlib originated from a privileged Soviet family. He has pectus excavatum and treated epilepsy, which he concealed from his wife (divorced after a nocturnal grand mal) and the Khrzhizhanovsky Power Engineering Institute, where he worked with sources of radiation (dismissed in the 1990s, later worked in construction). Epilepsy has a strong genetic predisposition [7]. As for pectus excavatum, it is known to be part of various genetic syndromes. Besides, Gotlib was noticed to uselessly damage trees working in pine tree tapping in Siberia in 1988 (Figure 4) [8].

2. Discussion

Many cases are known when a heritable disease was concealed from the partner and then acquired by the offspring. For example, 20- 25% people from East- and mid-European Jewish (Ashkenazi) descent carry certain disease-causing genes. This ethnicity is stressed here because no analogies in regard to other peoples are known. Approximately one in 10-15 Ashkenazi individuals are carriers of a mutation causing Gaucher disease, 1/30 – familial dysautonomia, 1/75 –Niemann-Pick disease; 1/40 are estimated to be carriers for Canavan disease, 1/89 - Fanconi anemia. The prevalence of various conditions is above-average in Ashkenazi people: diabetes mellitus, some cancers and leukemias, certain ophthalmic and other disorders; more details and references are in the Gale encyclopedia of genetic disorders [9-22]. Screening of the European Jewish population for recessive disease-causing mutations is recommended; one grandparent suffices to offer a genetic examination [23]. Israel plays an important role in the development of genetic counseling: more than 10,000 people are tested there every year. "Do not have children unless you are sure that they will be healthy both mentally and physically" [9]. This suggestion is not realizable in conditions of sexual coercion, contraceptive sabotage or concealment of a heritable disease from the partner or spouse. Some mutations are almost specifically Jewish, others are gathered and concentrated from surrounding peoples [20,21]. Inter-ethnic marriage may be consciously used against pathological consequences of incest [24]. A broad range of tactics is used by perpetrators: seduction and persuasion, alcohol and drugs, intimidation and violence, blackmail and financial pressure, as well as deceit including concealment of STI or genetic diseases (Chapter 7). Women should be aware of these tactics.

Another case observed by the author: a young individual (Aleksandr Kantsedikas, lithuanization of the name Kantsedik), who wanted to live in Moscow, concealed a hereditary condition from his 13 years older ethnic Russian bride. There were three medical doctors among his close relatives; his congenital

abnormalities were known and discussed. He had male Stein-Leventhal, otherwise named polycystic ovary syndrome (PCOS) equivalent, possibly combined with other derangements: gynecomastia and hypertrichosis, polythelia and inclination to overweight. Male PCOS was defined as a syndrome with signs of hyperandrogenism, PCOS-like metabolic pattern and familiar history of PCOS [25,26]. His daughter inherited PCOS and died in her fifties. Kantsedik was involved in child abuse and sexual violence [27]. He approvingly discussed with his father Solomon, World War II veteran and retired colonel, the torture of prisoners of war, using among others the phrases like "some Jewish guys could not control themselves" [28,29].

Sons of some high-ranking officers have been a known problem in the Soviet and post-Soviet society, being involved in immoral and illegal activities and professional misconduct [2]. High social positions held by perpetrators or their relatives prevented reporting. Another example has been published previously: a promiscuous son of a Soviet general knowingly spreading STI. The case was reported to authorities, and the whistleblower beaten at a later date (Jargin 2012, 2024) [3]. At the same time, many young relatives of superior officers, including all those mentioned here, evaded the mandatory military service under various pretexts. Another known case: a good-looking young man by the name of Lev Ginzburg concealed type 1 diabetes mellitus from his older ethnic Russian bride; the condition was inherited by the offspring. Similar cases of inheritance of Marfan syndrome are known as well.

In cases of sexual and reproductive coercion, contraceptive sabotage and family violence, it may be easy to expose a socially unprotected perpetrator. Otherwise, different tools can be used to prevent a disclosure: denial of facts and accusation of slander, threats and violence, tricks and provocations, appeals to uphold the honor and reputation of an institution, family, ethnic or confessional community. Some relatives of high-ranking officers or functionaries continue the misconduct, serving as models for the rising generation. Such cases may need administrative support and should be reported to the authorities.

Finally, the propensity for migrations and vagabondage is associated with certain genetic and/or ethnic characteristics. Migration may be desirable for people with abnormalities because behavioral and other deviations are less conspicuous abroad as the person is not typical just because he or she comes from another country. In a foreign environment, persons with abnormalities may be devoid of stigma at least temporarily [30,31]. "The grass is greener on the other side of the fence" not for everybody but for some individuals for certain reasons. Among the causes may be inherited features and/or affiliation with ethnic minorities. Another demographic problem, the gender imbalance caused by migrations, sex-selective abortions or female neonaticide, has been discussed by Jargin (2023) [32]. The growing excess of males contributes to their marginalization, antisocial behavior and militarism.

3. Conclusion

Genetic counseling should be broader applied in high-risk groups. Screening of Ashkenazi population for disease-causing mutations is recommended; one grandparent suffices to offer a genetic examination. More attention should be given to hereditary conditions at medical checkups and in the course of medical education. Concealment from a partner or spouse of a hereditary disorder may have grave consequences, and should be regarded as intentional crime if inherited by the offspring. This gives to a medical professional a moral right to disregard the obligation to secrecy, when it cannot be excluded that of the offender, his or her relatives would continue spreading the abnormal genotype or STI.

Conflict of Interest

The author declares no conflict of interest.

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