8. Infrastructuring DNA
Commercial genetic testing

Apart from mandatory and voluntary, formal and informal registers that are specifically designed for the donor-conceived and donors, there is another way of obtaining information about unknown relatives. Commercial genetic testing websites brought about significant changes for my field and some of my interlocutors during the time of my research, especially after I had already conducted the majority of my interviews. These sites differ in many ways from the registers already presented, and the tests that they sell are different from the type of genetic tests used by the DCR. DNA tests offered by companies such as 23andMe are sold directly to the consumer and have become a way to circumvent clinical and official regulations on donor anonymity.[1] In contrast to the central HFEA register, this possibility is available to all donor-conceived persons, regardless of when they were conceived, or where their donor had donated. Using DNA tests to identify donors or donor-conceived half-siblings is clearly not the main aim of neither those providing the services, nor of the main user community. Instead, genetic databases are mostly joined by people interested in genetic ancestry research (Klotz 2016: 46), or health reports (which are currently not permitted in Germany).[2] The appropriation of commercial genetic testing through the donor-conceived is thus an example of how infrastructures can be used in a way that differs from the intention of their designers (Akrich 1992).

1 www.23andme.com (last accessed May 28, 2020).

2 In my analysis, I concentrate on companies that offer autosomal (pertaining to chromosomes that are not sex chromosomes) DNA testing for genetic genealogy and have a matching database. Such tests are currently offered by Ancestry, FTDNA, 23andMe and MyHeritage. Besides, Living DNA offers ancestry analysis consisting of Y-DNA and mtDNA haplogroup reports, but does not currently have its own database for matching (www.livingdna.com, last accessed May 28, 2020). However, test results can be uploaded to GEDmatch if users want to search for genetic matches. A plethora of other tests are available as well. For example, Christofides and O'Doherty found 86 companies that offered direct-to-consumer genetic testing in Canada, with 29 of them offering health tests (2016: 108).

The use of commercial genetic testing to search for one's donor and donor siblings is a subversive way of using technology, as it can lead to "authoritative regimes of managing genetic knowledge" (Klotz 2016: 55) being bypassed. While the collection, storage and release of information on donors and treatments was previously controlled by medical professionals and/or state authorities, such systems and institutions are challenged by the emergence of new technologies and the way in which people appropriate them. DNA databases significantly change what can be known by whom and when, reconfigure the conditions of anonymity in gamete donation, and expand the ways in which information can be exchanged, shared and linked. Donor-conceived persons may learn about the circumstances of their conception through their registration with a database, instead of being told by their parents. They do not even have to be registered themselves, as their children might use these tests and get connected with their parent's genetic relatives (as shown in two of the case studies explored by Crawshaw (2017)). A particularly important feature of these increasingly popular databases is that they can enable the donor-conceived to identify their donors even if the donors themselves are not registered.

In view of these possibilities, it is increasingly argued that the anonymity of donors is a thing of the past: "the spread of genomic testing is likely to make anonymous gamete donation and parental non-disclosure highly problematic" (Harper et al. 2016: 1138; see also Brügge 2018).[3] Online commentaries have already started to play on words and use DNA as an abbreviation for "Donors not Anonymous" (Kramer 2016). However, my remarks on this subject, based on conceptual considerations and ethnographic insights, represent an attempt to break down the absoluteness of these statements. I suggest that a broad statement such as the title of Harper et al.'s article "The end of donor anonymity: how genetic testing is likely to drive anonymous gamete donation out of business" (2016) fails to take into account that anonymity is always partial and relational. A donor listed as anonymous by a sperm bank is anonymous only in relation to certain persons: while he remains unknown to the recipient parents, he is known to the person who registers him. To speak of 'complete' anonymity that has a clear beginning and an end is therefore misleading. Furthermore, my research has shown that the way DNA tests are used in the search for donor siblings and donors can be very complex. It is not an infrastructure that 'eliminates' anonymity, but a complex process of *infrastructuring* that makes things knowable and new connections possible.

Both my empirical material and my approach to the topic reflect the timing of my research: with two exceptions, I had conducted all interviews with donor-conceived persons before June 2017. That year, however, a change seemed to be taking place. Since December 2011, the German organisation Spenderkinder has

3 Harper et al.focus on SNP-based testing (2016: 1137), which will be explored in the next section (8.1).

encouraged donor-conceived persons to register with FTDNA, thereby creating an unofficial register (Klotz 2014: 268).[4] They recorded more and more half-sibling-matches especially in the second half of 2017. My impression that much was in motion in terms of DNA testing was also shared by an interlocutor from the UK, who was in touch with donor-conceived persons nationally and internationally via various Facebook groups: when I visited Elizabeth Chapman for the second time in summer 2018, she mentioned that from what she could witness online, "DNA testing has really blossomed".

A look at the statistics seems to support her and my impression that genetic testing was gaining in importance. In recent years, genetic databases have grown rapidly and have more and more members: for example, 23andMe's database had over two million profiles in 2017, compared to 800,000 in 2015 (Herper 2017). According to a popular blog run by a genetic genealogist, it had more than twelve million customers in May 2021, and Ancestry alone had a database with more than 20 million profiles (DNA Geek 2021). Nowadays, the apparent triumph of DNA testing seems to be an unstoppable process. This contrasts with what I was told when I conducted interviews in 2016 and during the first six months of 2017, which seemed to be a time when searching and waiting for matches instead of finding them was the most common experience of people purchasing a DNA test. Out of my interviewees who were interested in their donor and donor siblings, only four had already made a connection via a testing site when I met them, but five found at least one donor sibling or their donor after I had already interviewed them. Eight had registered but still not found a match that I knew of at the time of writing (May 2021). Additionally, five had not yet purchased a test, but had thought about it or already decided that they would do so in the future. The increase in the number of matches indicates that my research took place at a time when the conditions of anonymity in gamete donation were reconfigured through the way the donor-conceived use genetic testing.

This technology will be discussed in detail in this chapter. I will first explain what distinguishes this type of DNA testing on a technical level from the testing technology examined in section 7.6. I will also explore how these databases define kinship and ethnicity in a certain way, and why the test results are still uncertain. In

4 Another example for how the donor-conceived use these databases is the "Donor Conceived" FTDNA group (www.familytreedna.com/groups/donor-conceived/about, last accessed May 27, 2020), created in 2011 by Lindsay Manzoian-Greenawalt, an American donor-conceived activist who ran the blog *Confessions of a Cryokid* (www.cryokid-confessions.blogspot.com/, last accessed March 17, 2020). While the FTDNA group itself does not control the matching process, it does list the clinics where its members (126 as of May 2020) were conceived and can thus "encourage other donor-conceived people still undecided about whether to take the test, and […] highlight their need to the wider community for finding their genetic relatives" (Crawshaw et al. 2015: 75).

the next section, I will examine the complex processes of infrastructuring, through which some donor-conceived persons tried to combine results of their online and offline search in order to obtain information about their donor even if he was not registered. Afterwards, I will address the fact that even those who were not willing to take such measures still felt that they had to at least try to find their donor and donor siblings with a DNA test. In the last section, I will discuss how the waiting for a genetic "match" has evolved with the increased yet slowed down growth rates of DNA databases.

8.1 Relationship ranges, ethnicity estimates: Measuring kinship and ancestry

In genealogy blogs and forums that facilitate exchanges between genetic genealogists, the tests used by companies like FTDNA are often described as superior to STR tests. They are said to measure the amount of shared DNA and be more than just a statistical 'guess'. In the following pages, I will take a brief look at what makes the tests offered by commercial websites different. I will show why the connections that can result from these tests are not the result of a straightforward measurement process, and that the interpretation of these results often requires additional information and research. Nevertheless, this section also highlights that the results are always based on kinship categories defined by the respective database. Finally, another important feature of these databases will be addressed: while my interlocutors may have attached little importance to what another platform called MyHeritage calls "ethnicity estimates", the popularity of such estimates seems to be partly responsible for the rise of genetic testing. For this reason, the measuring of "deep ancestry" will be discussed briefly.

While tests used for the DCR register and forensics examine STRs, FTDNA's popular test "Family Finder" and the genetic ancestry tests offered by Ancestry, 23andMe and MyHeritage examine Single Nucleotide Polymorphisms (SNPs; pronounced "snips" in laboratory and genetic genealogy jargon).[5] SNPs are variations in the order of nucleotides that occur when a specific nucleotide is different from what the majority of the population would have. When most individuals of a population might have the nucleotide "A" at a specific location, one percent might have

5 I followed the advice of my interviewees and used genetic genealogy blogs and websites to better understand DNA testing, and I found the website of the International Society for Genetic Genealogy, which is a volunteer-run organisation, particularly informative (www.isogg.org, last accessed May 31, 2021). Those of my interviewees who were particularly involved in the "infrastructuring" of DNA also recommended genetic genealogist Kitty Cooper's blog to me (https://blog.kittycooper.com, last accessed May 31, 2021).

a "G". SNPs mutate less frequently than STRs, which results in specific sequences being passed on unchanged across generations.[6] If two persons have a number of consecutive SNPs in common, they are said to share a segment of DNA. Whereas one will share larger segments of DNA with close relatives, the amount of shared DNA will decrease if the "most common recent ancestor", from whom two persons have inherited a SNP, is more distant. The more distant this ancestor is, the more distant the genetic relationship between them will be. The number of shared centiMorgans (cM) indicates how much DNA two persons share, with a high cM value indicating a larger amount of shared DNA and thus a closer relationship.[7] Genetic databases not only detect genetic connections between close relatives, but also more distant genetic links, and the majority of my interviewees had only found more distant relatives, with whom they only shared a small amount of cM. Their most common recent ancestor, from whom they and their "genetic match" had descended, had mostly lived several generations or centuries ago. Such matches or distant genetic relatives are also referred to as "genetic cousins", which are differentiated by two main categories: degree and removal. The "degree" of a cousin relationship indicates how far back in the family tree the most common recent ancestor is located, whereas a "removed" cousin relationship indicates that two relatives are from different generations.[8] Remarks about "third" or "fourth" cousins that were "once" or "twice removed" were scattered through many interviews when people talked about their test results, as most of them had not yet found any donor siblings or the donor.

One might share the same amount of cM with various relatives.[9] However, algorithms are not able to distinguish between different types of relatives who might

6 Commercial sites test between approximately 630,000 and 700,000 SNPs. These specific locations on the genome are then compared to the results of others who are already on a database.

7 For practical purposes, cM values are oftentimes talked and written about as if they measured length, and I do the same here. However, cM is in fact a measurement of probability. FTDNA's Learning Center defines cM values as "measurements of how likely the segment is to recombine as it passes from parent to child. Segments with higher cM values have a greater probability of recombining in any one generation. Therefore, when you share DNA segments with larger cM values with a match, your common ancestors are likely to come from generations that are more recent." (FTDNA, n.d.)

8 Whereas one shares one set of grandparents with a first cousin, second cousins will have a set of great-grandparents in common. When a cousin relationship is "removed", it means that one cousin has a closer relationship with the most recent common ancestor in terms of generational distance; removed cousins are thus separated by at least one generation. A "first cousin once removed" relationship exists between a person and their mother's first cousin, as well as between a person and the children of their first cousin.

9 For example, one shares on average 25 % of one's DNA not only with a half-sibling but also with a grandparent, an aunt or uncle, and a niece or nephew.

share a similar amount of cM with the person taking the test. Besides, they are not able to detect every genetic cousin. About ten percent of all third cousins will not share enough DNA for the relationship to be detected by an algorithm.[10] For these reasons, additional information is usually needed to determine the exact nature of a match, to make sure that a supposed match is not actually a false positive one (Abel 2018), or to find additional branches of one's family tree that have not shown up in a test. Any additional research needs to be conducted by the person taking the test, and is not done by the testing company, although some of them offer a collection of digitised historical records that can be used for further research.[11] The lack of certainty concerning the interpretation of results is also reflected in the way in which they are presented. Registrants will usually be presented with a possible "relationship range" that indicates the possible relationships between two persons. Various blogs and other online resources can then be accessed in order to interpret test results.[12] While tests might not determine the exact nature of a relationship, they are nevertheless prescriptive with regard to the type of relationship that is conceivable in genealogical terms. For example, FTDNA might state a relationship range as "Half Siblings, Grandparent/Grandchild, Uncle/Nephew". The registrant might then choose "Half Sibling" as the actual "Linked Relationship" but would not be able to enter "Parent" in this column. The kin terms used by such sites and the way in which they order relationships are consistent with Euro-American kinship thinking, where "kinship is whatever the biogenetic relationship is" (Strathern 1995:

10 Third cousins have a great-great-grandparent, who is four generations 'away' from them, as their most recent common ancestor.

11 Ancestry and MyHeritage offer a large collection of digitised historical records. However, access to these documents is not included in the DNA test and must be purchased separately. In addition, Ancestry has been offering the ThruLines™ tool since 2019. It shows how a person on the database may be related to their genetic matches, and is based on information from family trees. Ancestry points out on its homepage that the tool is only reliable if the family trees contain accurate information: "Since ThruLines™ are based on the family trees of you and other members of Ancestry, they're as accurate as the trees they're based on. Mistakes in family trees can cause inaccurate ThruLines™. Because they're based on trees, ThruLines™ don't prove your specific connection to a DNA match." (AncestryDNA, n.d.)

12 The Shared cM Project, initiated in 2015 by popular genealogy blogger Blaine Bettinger, is an interesting example of such a tool. Bettinger describes it as "a collaborative citizen scientist project" (2016: 38) to which everyone who has undergone genealogical DNA testing can contribute by submitting information about the number of shared cM with known relationships. On the basis of the submitted data, a minimum and maximum of cM for a given relationship is calculated, as well as an average. The results are displayed in a "Relationship Chart", the fourth version of which was launched in March 2020 (https://thegeneticgenealogist.com/wp-content/uploads/2020/03/Shared-cM-Project-Relationship-Chart.png, last accessed May 07, 2020).

348). While these tests are available worldwide, they do employ an understanding of kinship that is not universal.

STR testing is not entirely absent from the commercial database offering, although none of the people that I talked to mentioned having purchased this type of test for themselves.[13] STR tests are mostly used to give information on "deep ancestry" instead of more recent relatives. They are used to establish a person's haplogroup, which, in a genetic genealogy handbook, is defined as a "[g]roup of individuals who share several genetic mutations as well as a common (usually ancient) ancestor" (Bettinger 2019: 280). Haplogroups are commonly understood as a means to obtain information about "a person's descent from "founding populations" that inhabited regions and continents of the earth thousands of years ago" (TallBear 2013: 41). In addition to SNP testing, which pertains to chromosomes that are not a sex chromosome, males also have the option of having their Y-chromosome tested, which is passed on only from father to son (or from sperm donor to male offspring). While SNP-based testing can mostly be purchased for less than US$100, Y-DNA testing is more expensive, although prices for this type of test are decreasing as well.[14] As the paternal ancestry line corresponds to the inheritance of surnames in many cultures, such testing can potentially reveal the donor's surname.[15] Another testing option is mtDNA testing, which tends to be of little significance for those searching for their anonymous sperm donor, as it examines a part of the

13 Nadine Fuchs, whose brother had been conceived with sperm from the same donor, had paid for her sibling to have an additional Y-DNA test.

14 FTDNA's basic Y-DNA test tests 37 STRs and was available for US$169 in September 2019. The company's "Big Y-700" test, advertised as giving information on an "expert level," examines 700 STRs as well as 100,000 SNPs and was available for US$649 at that time. In January 2020, the basic test could be purchased for US$119, and the 'expert' version was available for US$449.

15 The "surname projects" that those who have tested with a specific company can establish within a database "utilize[…] the logic of crowdsourcing" (Stevens 2015: 396), as they rely on registrants to provide their test results in order to establish whether people with the same surname are genetically similar.

DNA that is passed on from a mother to her children (or from egg donor to donor offspring).[16]

Even when customers do not purchase a "deep ancestry" test, they can still access maps that provide them with a geographic breakdown of where their ancestors came from when viewing their test results online. This information is referred to as "ethnicity estimate" by MyHeritage, which only started to offer its genetic testing service in 2016 but seemed to quickly gain popularity amongst my interviewees. MyHeritage prides itself with offering 42 ethnicities. Their "ethnic groups" are split into six categories (Africa, America, Asia, Europe, Middle East, Oceania). Ethnicity estimates are contingent not only on the membership of a testing site but also "on the contents of their reference population database, as well as how they categorize and label their results" (Abel 2018: 4). As a result, "the estimates provided by different companies can vary wildly" (Abel 2018: 3). While MyHeritage lists "Nigerian" as an ethnic group, FTDNA does not (ibid.). These estimates were not the main reason why my interviewees, who were interested in closer relatives, bought these tests, although a few people had mentioned that they had hoped to find out more about the donor's ethnicity. When people talked about their results, they referred almost exclusively to the list of their genetic matches, and only rarely to their ethnicity estimates. However, it is striking that the ethnicity aspect is clearly emphasised in the way tests are advertised. Apart from the possibility of finding unknown relatives, advertising focuses on the potential of these tests to enable people to find out where they and their ancestors "really come from". MyHeritage, for example, promises its users on its webpage that their "simple DNA test can reveal your unique ethnic background, and match you with newfound relatives".[17] Various databases have sponsored videos on YouTube in which content creators discuss their test results with their audience and reveal where they "originally/really come from".[18] The extent to which the desire to find out more about one's ethnicity and "deep ancestry"

16 mtDNA testing looks at the mitochondrial DNA passed on from a mother/egg donor to both female and male children/offspring. In September 2019, mtDNA testing was available at FTDNA for US$89 for a basic version or US$199 for the "mtFullSequence". In January 2020, it was only the extended version that could be purchased for US$159. Nobody that I had spoken to had purchased or even just mentioned this kind of testing, which arguably reflects the fact that, apart from one exception, my interviewees were all sperm-donor-conceived. A few of them did in fact have a keen interest in their maternal ancestry as well. They felt that this was fuelled by their maternal line being the only 'branch' of their family tree they could find out about (see for example Tamara Haste in section 8.2). However, testing mtDNA to find out even more about the known side of one's tree was not something anybody had considered.

17 www.myheritage.com (last accessed March 08, 2020).

18 See Lily Pebbles (2018) for an Ancestry-sponsored video in English, and Jessi Cooper (2018) for a MyHeritage-sponsored video in German.

is behind the increase in sales figures is a question that calls for further research on genetic testing.[19]

Kim TallBear's work (2013) on genetic ancestry testing in the US offers an insightful critique of this type of DNA analysis. In her monograph *Native American DNA* (2013), she argues that the genetic markers used in ancestry tests "have not been simply uncovered in human genomes; they have been conceived in ways shaped by key historical events and influential narratives" (2013: 5). According to TallBear, "[t]he concept of Native American DNA is […] constituted of relations between molecules, happenings, instruments, and minds" (2013: 32; see also Bardill 2014) instead of being something that is 'out there' to be discovered and classified. While ancestry tests, which are supposed to detect "Native American DNA" through a check swab, deploy the logic of lineal descent, TallBear has shown that this is "a biological concept that is not always compatible with "traditional kinship" concepts or with contemporary ways of determining tribal membership" (2013: 155). Companies and tests have evolved considerably since TallBear started studying the market in 2003 (2013: 69). However, her work seems even more relevant today, with MyHeritage presenting "Native American" as one of the database's 42 ethnic groups.

Commenting on what she perceives as an "overwhelming America-centric bias" in research on genetic testing, anthropologist Katharine Tyler suggests that studying the use of genetic ancestry testing in the UK could provide a "specific ethnographic insight into the ways in which these tests are mobilised and their results interpreted in the context of postcolonial Britain" (2018: 1). She proposes a research agenda that specifically focuses on Britain, "[t]aking on board the specific histories of empire, slavery, race, nation, racism, nationalism and multiculturalism that have formed and continue to shape the UK and its ethnically diverse citizenry" (ibid.). I suggest that focusing on German genealogists and their use of genetic ancestry testing could add yet another perspective on how ideas about ethnic and other identities are conceptualised. Occasionally my German interlocutors told me that they were sometimes accused of being attached to a Nazi-like racial ideology due to their interest in their origins, which they always firmly rejected. In view of the strengthening of nationalist movements in Germany, I would nevertheless suggest that further research on genetic ancestry testing should look at how ideas about national identities and belonging are discussed by those interested in DNA tests and "deep ancestry".

19 What I was told in Germany points in this direction: for example, one of my interviewees found a donor sibling after the interview. Her donor-conceived half-brother had not known that he was conceived with donor sperm. He had received a test kit from MyHeritage as a gift from his wife, who was interested in the company's ethnicity estimates.

8.2 Digital DNA: Working out relationships and infrastructuring information

Via genetic testing, participation in a digital world and genetic material gets merged (Ruckenstein 2017: 1026). Most importantly, genetic databases offer not only DNA tests whose results can be viewed online and exported to other sites but also ways of communicating online with other users. As I will argue, this can pose new challenges for the donor-conceived, although (or because) it might bring them in touch with donor siblings. I will also show how some of my interlocutors attempted and sometimes managed to combine information from a variety of sources to make the best use of their test results and 'work out' genetic relationships. This illustrates that DNA testing does not end anonymity, but that it opens up new ways of linking information. It is this process, which I call infrastructuring, that calls into question whether a distinction between identifying and non-identifying information can be made with certainty. I suggest that a distinction is challenged by new ways of connecting, circulating and networking information. The boundaries between what can be used to identify donors and what keeps them anonymous get blurred.

The tests offered by FTDNA, Ancestry, 23andMe and MyHeritage are increasing rapidly in terms of scope and accuracy and implement developments in genetic testing faster than voluntary registers. Additionally, prices continue to fall: FTDNA's test "Family Finder" was sold for US$300 when it was first launched in 2010 (Stevens 2015: 394) and was available for US$79 in May 2021. Besides, testing companies frequently hold sales not only at official holidays but also on occasions such as "DNA Day",[20] during which the tests can be bought at a reduced price. It should be noted that even though they have become cheaper, not all of my interlocutors were able to afford this sum. However, the prices were something that made people postpone a purchase rather than give up the thought of it altogether.[21]

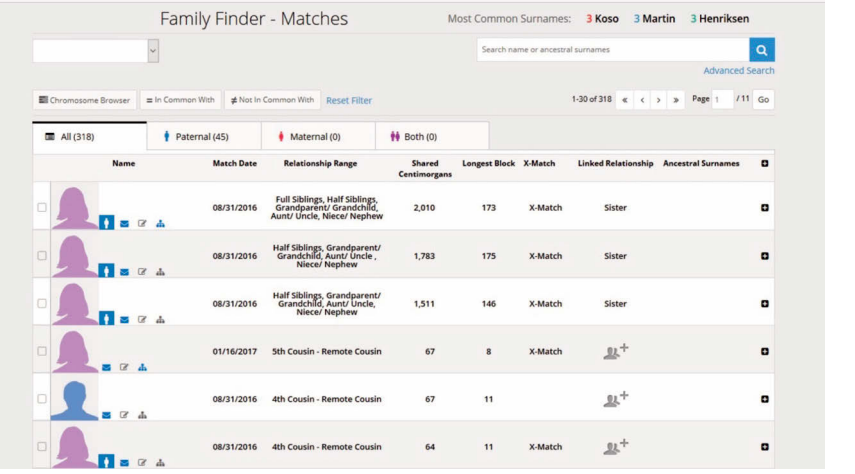
After buying a test kit online, sending in a saliva sample for analysis to the company's laboratory, and receiving a notification email about the results, customers

20 DNA Day is celebrated on April 25. It commemorates the discovery of the double helix structure of DNA in 1953 and the completion of the Human Genome Project 50 years later. In the US, it was an official holiday in 2003 only and merely supposed to be a one-time celebration. However, the National Human Genome Research Institute continued to organise a yearly DNA Day, and other groups have since started celebrating it as well.

21 Jacob Moore, for example, was still attending university when I interviewed him. Although he had "definitely considered" purchasing a test, as he was keen to find his half-siblings and learn more about his ancestry, he had not yet been able to do so: "I mean the problem with those things is they're all not very expensive but a little bit costly, and as a penniless student I can't really afford that at the moment." He was planning on doing at least one DNA test once he had the money for it.

can log into their accounts, view their own data online, and see how they are related to other persons on the database. In the case of FTDNA (figure 4), this data is presented in the form of a table that lists other registrants and the specific relationships that are possible based on the amount of shared cM.[22] Registrants can then enter the "linked relationship" in a specific field. If matching is not enabled, a person's data will not be matched with that of other users. Those who decide to participate in the DNA matching feature have to consent to information such as their email-address and profile picture being made available to genetic matches. The matching features of other companies are optional as well, and registrants can usually decide to opt in and out of DNA matching at any time after the registration process. Customers can connect with other users via messaging functions, or even access the email-address of a genetic match in the case of FTDNA's matching service, discuss their findings, exchange messages and family trees. The opportunity to get in touch with others gives them the chance to discuss test results and work out how a match came about.

Figure 4: Screenshot of FTDNA results



Source: Sabrina Frey

Apart from purchasing a specific company's own tests, users also have the option to export 'raw' genetic data and upload it to other sites (Ruckenstein 2017: 1026), although not every company offers the same import and export options. Raw data files contain thousands of lines that consist of the information for all of the

22 The original list contained both names and profile pictures.

SNPs that were tested. Without any analysis tools, raw data documents appear to be nothing more than endless strings of letters and numbers. There are several online platforms that can serve as analysis tools but do not offer their own DNA test. It was notably the genealogy website GEDmatch that seemed to be popular with those who made particular intensive inquiries to find their relatives.[23] The site is free of charge but does offer several "premium tools" that can be purchased by users. The possibility of exporting and importing raw data demonstrates that in the context of online DNA databases, genes are presented "as digital big data to be browsed, uploaded and shared" (Hogarth and Saukko 2017: 202). Uploading results to other sites and registering with several companies in the hope to maximise one's chances of finding a donor sibling or the donor was a phenomenon that I first encountered in the UK. Several of my British research contacts had already registered with multiple sites by the time I met them. In contrast, Nadine Fuchs was the only one of my German interviewees who had already registered with more than one company when I did my research. She had also started to use GEDmatch in her search for her donor.

The possibility of directly contacting other people on the database constitutes a significant difference between commercial genetic testing and registers such as the central HFEA register, the DSL, or the DNA database managed by the DCR. Whereas these formal registers act as intermediaries in the case of a match and usually offer psychosocial support for those with newfound relatives, commercial genetic testing sites do so far not offer a comparable service. Instead, people get directly in touch with each other without the mediation of a third party. While commercial databases can be seen as empowering donor-conceived people, as they are not dependant on an intervening third party to establish contact, there are also more critical and sceptical voices lamenting the lack of support (see for example Crawshaw 2017).[24]

My interviewees themselves pointed out that genetic testing might potentially bring the donor-conceived into challenging situations, particularly as they might get matched with donor siblings who do not know yet that they were conceived with donated gametes. Elizabeth Chapman, for example, told me about the experience of one of her donor-conceived friends who had been matched with a donor-conceived half-sister. She had not yet known about the circumstances of her conception and had soon after broken off contact with Elizabeth's friend. Elizabeth

23 www.gedmatch.com (last accessed March 08, 2020).

24 The question of support and responsibilities is addressed by Crawshaw in a commentary on donor conception and commercial genetic databases (2017). She argues that given their growing popularity, it is increasingly necessary to raise questions "about their ethical responsibilities to provide additional information about where their customers can turn in the event of uncovering the probable presence of donor conception" (2017: 4).

commented, "It's a lot to take in, isn't it? And to find out that way, when you're interested in genealogy, and to suddenly find out you've got a half-sibling." However, she pointed out that it had also been a difficult situation for her friend since "that puts a lot of onus on donor-conceived people […] to be careful how they frame things when they talk to people". Some of the concerns discussed in chapter 6 become relevant here at a different level. The question of who knows what at what point in time and who can, should or may tell others, and how things need to be 'framed' needs to be re-addressed. Those who already know that they are donor-conceived have information that is constitutive for their genetic match. However, they must find a way to convey it without causing any kinship trouble.[25]

Whereas the central HFEA register and the DSL each have a minimum age for accessing information or joining the database, minors can usually take a DNA test if their parents give their consent. This makes it possible for parents to register even small children (as exemplified by the case described in the concluding chapter).[26] And whereas registers such as the DSL and the central HFEA database only match the donor-conceived with their donor siblings, or with their donor, commercial databases establish links between distant "genetic cousins" as well. A match was only considered useful by my interviewees if the cousin they had been matched with was of a relatively low degree, and not too far removed. Elizabeth had shown me various testing sites and the accounts as well as matches that she, her husband and one of her donor-conceived friends, whose accounts she managed, had on them. She argued that whereas a third cousin could be a good enough match to find a donor, more distant cousins were usually not sufficient. Elizabeth summarised it as follows:

> Elizabeth Chapman: "You just find your cousins, and then you have to try and work out relationships. You do need to find close matches though. It's no good finding a sixth cousin, you do need a first or second or third cousin. But some have worked it out from third cousins. It's marvellous, it's revolutionist, it's fantastic."

'Working out relationships' required putting in effort and having matches that were 'close enough'. However, Elizabeth knew of donor-conceived people for whom finding more distant cousins had worked:

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25 In a blog post on the subject, Spenderkinder (2019b) advises the donor-conceived to be cautious when they have a match and not to ask immediately in which clinic the other person was conceived. Instead, the author suggests to first ask why the other person has taken a test, and argues that it is "patronising" (*bevormundend*) to advise them to talk to their parents first "because if you register with a DNA database, you are an adult and can decide for yourself what you want to know" (2019b, author translation).

26 FTDNA does not allow persons younger than 13 to take a test, while other databases do not have a minimum age. However, they also require a parent or legal guardian to give their consent if the person to be tested is under 18.

> Elizabeth Chapman: "If you can see their family tree, you can work it out, you go down a few generations, and you find out if they've had someone who trained to be a doctor or went to a university, you can tell, 'Oh yes they went to such and a university in [a town], oh, was he there in the 1970s, yes, he was there in the 1970s, when [her friend] was born', and you think, 'Ah'. And that'll give you a good idea. And it has worked. People have found their father that way."

It is not only genetic material and digital participation that gets merged when people are working with DNA tests, but also other forms of knowledge people might have, such as information on the profile past donors are likely to have had ("student in town X where treatment took place"). Moreover, genetic testing does not replace other methods of searching. Many of my interlocutors used various other online and offline resources. They visited physical archives, libraries and the clinics where they had been conceived to search for information. This was especially the case among donor-conceived persons in Germany, as there were no official or voluntary registers that they could use. Most of them did not access these resources with the explicit intention of linking the results of their offline search with the results of their DNA test. However, infrastructuring practices that interweave information from different resources could become a powerful, albeit work-intensive, means of searching for those who did not have close matches.

The story of Nadine Fuchs, who was conceived in Germany in the late 1970s, is a particularly striking example of the infrastructuring of information. While others spent time in archives and libraries out of an interest in historical contexts and were driven by curiosity, pain and the desire to overcome it seemed to drive her search. Compared to what other people told me, her experience is unique in terms of the time and other resources she invested in her search. Nevertheless, I will summarise it in the following paragraphs, as the complexity and creativity of infrastructuring can be shown particularly clearly by the rather 'extreme' nature of her story. Although no one else invested as much time and work as she did, her experience of unsuccessfully contacting doctors was something that was shared by many of my German research contacts.

A central theme in Nadine's story was the feeling of not fitting into her family and being completely different from her parents. Like many of my interlocutors (section 5.3), she mentioned that she was the first in her family to attend high school (*Gymnasium*). Instead of being proud of her, her parents had shown little support and understanding, and constantly asked questions such as "Do you think you are better than us?" Since she had always felt like a stranger in her own family, she had not been shocked at all when she learnt that she had been conceived with donated sperm. Her constant feeling of not fitting into her family had not deceived her. However, she had soon felt another kind of 'dissonance', which prompted her to search for her donor immediately. Nadine mentioned that when she had looked

in a mirror, her face had no longer "fitted". She had felt as if she was looking at "an alien being" (*ein fremdes Wesen*). She had immediately felt a strong urge to find her donor, "so that this gap can be closed. So that someone would be there."

Nadine was very critical of donor conception per se and argued that couples who thought about using donor sperm should take into account that a man might "suffer terribly from the fact that he does not have the same relationship with the children, that he cannot love them as much as his wife". Her own father had never really been a "present" parent, with other male figures such as her grandfather or even a neighbour being more involved in her and her brother's lives. For her, adoption was the preferable 'solution' for involuntary childlessness, as it resulted in 'even' relationships with neither the mother nor the father being genetically related to the child, and with both parents having "the same access [*Zugang*] to the child". Others voiced similar opinions, although not all were critical of gamete donation.[27] Statements according to which adoption creates a balanced "access" to the child reflect a belief in the idea that "each parent must somehow occupy a position with respect to the child that can be understood as similar or the same in some crucial aspect" (Melhuus 2012: 43), with DNA not being the only way of ensuring an equal or even connection.[28]

Since the doctor who had performed the insemination in the 1970s had already died, Nadine had contacted the physician who had taken over his gynaecological practice. However, he claimed that all documents that might contain information about the treatment and her donor had already been destroyed. Other donor-conceived persons that I interviewed in Germany talked about similar experiences. Most of them had contacted their mothers' doctors or the clinics where the inseminations had taken place. In some cases, the clinics and physicians maintained that access to information could not be granted for legal reasons. They did not necessarily state that the documents had been destroyed. Some of the people I interviewed had been met with little understanding when they contacted clinics and sperm banks. For example, one person had been told by a doctor that her parents

27 In contrast to Nadine Fuchs, Sabrina Frey repeatedly mentioned that she considered donor conception to be a perfectly acceptable practice. She believed that fathers in particular should be proud instead of ashamed of having chosen this path to parenthood (section 6.1). She nevertheless made a very similar argument regarding the 'evenness' of genetic connection. Sabrina mentioned that she would have chosen adoption over donor conception if she or her husband had been infertile, as she thought it was "fair that then both are not the genetic parents. So that nobody gets excluded."

28 The importance of having a child that equally belongs to both parents was also highlighted by the couples in Melhuus's (2012) study on involuntary childless couples in Norway. Some of them decided for adoption and against donor conception because they did not want to "risk skewing the parent-child relationship in favour of one or the other, and thereby also, in their understandings, undermining the conjugal relation" (2012: 43).

who had raised her were much more important than her donor. Unsurprisingly, he did not give her any information about him. Many were upset by such reactions and stated that they did not believe that the doctors who claimed that they had no treatment records left were telling the truth. Interestingly, a few people told me that they could in fact understand when doctors refused to give out information (see also section 3.5). Diana Kraft from Germany, for example, who had been told by a doctor that even if he still had documents, he would not give her information about her donor, told me that she could understand him: after all, he had promised past donors that they would remain anonymous. Diana believed that if doctors had given their donors this kind of promise, "then they have every right to keep that promise, even if it is at the expense of the children".

However, an inquiry could also be successful. In the case of another person, who had been conceived in the late 1980s, the doctor, after initial hesitation, eventually arranged contact between the donor and my interlocutor. He had also initially claimed that all documents had been destroyed and had only become more cooperative after she had told him that, if necessary, she would sue him for information. These experiences illustrate that, in the absence of a central register and clear regulations, doctors in Germany exert or try to exert more control over information than their British colleagues. At the same time, however, this can also create new opportunities for action for donor-conceived persons, as it can lead to doctors having to appear in court. This was what happened in the case of another one of my German interviewees who did successfully sue a doctor for information about her donor.

While Nadine's research into the late doctor's professional and family environment had been unsuccessful, the two DNA databases she had already joined seemed more promising, even though she had no close matches at the time of the interview. Nadine had not only her own genetic data to work with but also the test results of her brother and a maternal aunt, who had also agreed to be tested. Her aunt's data allowed her to 'filter out' her maternal matches from her match list and focus on her paternal matches. Her brother's registration had revealed that they had the same donor, which her parents had not known. This finding was especially helpful for Nadine, as it meant that she could use his genetic data to better assess the actual significance of her own matches:

> Nadine Fuchs: "So it's not always the case that someone with whom you share an incredible number of genes is necessarily very helpful. Sometimes it's the other way around. Because the good thing is that I have my brother, and we are full siblings, and sometimes it's a very high match with him, and I see that it's a very low match with me. Simply because we are different, because the genes are differently distributed and scattered."

Although all of her distant cousin matches lived far away in the US, Nadine mentioned that "real friendships" had developed in the meantime. The newly formed group of cousins exchanged not only genealogical information but also messages such as birthday wishes. Many of her matches had put their family trees online, which they constantly updated and expanded with new information. By carefully searching and comparing these trees, Nadine had been able to identify the person who linked the different trees, making him the most common recent ancestor of her and her cousins. The genealogical research of her cousins had revealed that this person had been born in eighteenth-century Germany. Nadine concluded that another descendant of this person must have been her donor. However, since her ancestor had died long ago and probably had thousands of descendants, she knew that it would be impossible to recreate his complete family tree, locate all his descendants and find her donor. Apart from the sheer number of people she would have to check, her search was further complicated by the fact that the existing data was probably incomplete. Although the genetic genealogy blogs she used to read up on DNA testing and the Facebook groups she had joined to exchange information with others were helpful, they did not lead to a breakthrough.

In the meantime, Nadine had also discovered a doctor through an intensive Google search, whom she believed could be her donor. After she had been 'scanning' images of doctors online for a long time, she had come across a physician who had not only studied medicine in the city where she had been conceived but who also looked like an older version of her brother. This doctor had denied ever having been a sperm donor when Nadine contacted him. Nevertheless, she had started to research his family history intensively, without him being aware of her search. Her goal was to find a connection between his family tree and the trees of her genetic cousins. To achieve this, she had already spent many hours in archives, some of which were located in other parts of the state she lived in, trying to trace and build his family tree. Although she had already invested an enormous amount of time and effort, she did not limit her search to him: "I also follow up on others, so I try somehow not to be guided by my feelings, but I also try to really think *out of the box* [she said this in English] […] I try everything." Since she did not know who her donor was, she felt compelled to follow up several leads at the same time. Her attempt to trace the family tree of her brother's lookalike in particular, without the doctor being aware of her efforts, illustrates that she did engage in a detective-like search, a practice that has also been described as "technological sleuthing" (Nelson and Hertz 2017: 153).

Sometime after the interview, she bought another test, which was not yet available in Germany at that time and which she had therefore ordered through a friend living abroad. At this point her search seemed to be at a dead end, and Nadine mentioned in an email that, for the first time, she had decided to stop searching. This test was her last attempt to find out something. However, this time Nadine was

lucky to get a very close match immediately. She recognised the last name of this genetic cousin, as she had come across it during her previous investigations. She had already 'built' this part of the family tree some time ago based on an intuitive feeling that made her return to this particular family again and again. For this reason, she knew immediately where exactly in her family tree this new match was located. Nadine concluded that one of her match's three maternal uncles had to be her donor. Nadine knew, "thanks to the Internet and Google", that the wife of one of these men had studied in the city where she was conceived and assumed that her husband would probably be her donor. Through an inquiry at a registration office (*Einwohnermeldeamt*), she managed to get his address.[29] Nadine sent him a letter, to which she attached a photograph of herself. He contacted her by email a week later and said that he had not expected anything like this. It turned out that her donor was in fact not a former medical student. Instead, he had met the doctor who had performed the insemination of Nadine's mother through his wife, who had once been his patient. In the meantime, Nadine and her donor had also met in person. Although no close relationship had developed, she wrote me that she was happy and relieved to have found him: "I have found my peace." Up to now she had not had any contact with his children, who were her genetic half-siblings, but not donor-conceived. Her donor did not seem to want them to know about his past donations, and Nadine did not want to initiate contact against his will.

Before returning to the infrastructuring of DNA, I will briefly discuss how donor-conceived persons reacted when their donor, as was the case with Nadine, did not meet their expectations. While they did not necessarily imagine their donor as a likeable person, many seemed to hope and expect that they would meet a man they could respect and admire. In particular, many seemed to imagine their donor as an intelligent, ambitious and professionally successful man (see also section 5.3). Based on what I have heard from, or read about those who have identified their donors, I would say that in many cases their expectations were not met. Nevertheless, even in these cases the donor-conceived usually commented that they had "found their peace". I suggest that similar to the way people talk about having always felt the truth (section 5.2), "finding peace" recreates a sense of continuity and

29 By making a request to a resident register (*Melderegister*) managed by a registration office, private individuals can obtain limited information about other residents. These requests are fee-based. Extended information, which includes the date of birth and marital status, is only provided if a "legitimate interest" (*berechtigtes Interesse*) can be demonstrated. Such circumstances include, for example, a dunning procedure. It is possible to apply for a two-year ban on one's own data so that it cannot be released. In Germany, I was told about a person who had located her donor by making a request for his address after she had found out his name. After she had contacted him, he had his data blocked, and another person was later unable to request his information. Out of respect for the donor's decision, the person who had already received his data had decided not to give it to her.

coherence. Something that could have become a painful experience – that is, not finding the kind of donor one had hoped for – is narratively reworked into something that does not bother them too much.

Not all of my interlocutors were willing or able to put this much time and effort into continuing their search on the basis of more distant genetic matches. Some did not want their search for the donor to get out of hand, while others did not seem to be aware of the possibilities a distant cousin could create. Still others mentioned that they would like to put more effort into their search, but had not yet found the necessary time to do so due to professional or private obligations. Tamara Haste, for example, had been matched with a fourth cousin with whom she was in email contact and who had given her information about his ancestry. Like others who had made contact with genetic cousins, Tamara had done so in the hope of ultimately identifying her donor. Since she loved history and "anything to do with the past", Tamara had already started to do 'conventional', non-genetic ancestry research on her maternal ancestors after she found out she was donor-conceived. She explained that this was "the side that I can find out about" and commented that tracing her maternal ancestry back over several centuries had been "quite satisfying". The family tree she had been given by her distant cousin did not match any of that information, and Tamara therefore suspected that he might link her to her unknown paternal family, and not to her known maternal one. However, due to her full-time job, she did not have the opportunity to invest a lot of time in the search. Finding the most common recent ancestor of her and her match seemed impossible, at least for now, which frustrated her. She had not yet succeeded in becoming involved in campaigning for the rights of the donor-conceived either, although this was something that was close to her heart as well: "It's something that is difficult to make a priority when you've got other stuff going on, but at the same time it's something you think about literally every day."

Elizabeth, whose thoughts on 'working out relationships' I have commented on at the beginning of this section, had made searching for genetic relatives a priority. When I met her for the first time, she not only showed me FTDNA as well as GEDmatch on her laptop but also talked at lengths about how the emergence of the Internet, PCs and emails in the mid- to late-1990s had helped to establish an international community of donor-conceived people and other activists (section 4.1). She concluded that without these technological developments, neither connecting with others nor finding one's relatives would be possible and proclaimed that the Internet had "revolutionised things" for the donor-conceived. Nevertheless, she also pointed out that despite new possibilities such as online groups and genetic testing, finding one's donor was still dependant on fortunate coincidences. The revolutionist potential of genetic testing could only be unfolded if a 'close enough' match was made, which depended on who else joined the database:

> Elizabeth Chapman: "Without the technology, hardly anything would be possible. […] I mean this FamilyTreeDNA … [shuts down her laptop] it's wonderful, really. You don't even have to leave home. You can find your father now without leaving home, you don't even have to go and pay for it because you use your credit card online. And the stuff comes, it's delivered to your door, the hardest bit is going to the post office to send it back. And then everything is done, and you can actually find him. It's amazing really. But you do need the luck. So not everybody's going to be lucky. Which is a shame."

Even with DNA testing, there was still no guarantee that one would be successful, as there was an element of chance and good luck involved as well. Elizabeth framed genetic testing as something that was accompanied by a high degree of unpredictability, which was again emphasised by the comparison she drew later on between genetic testing and gambling: "There are lots of opportunities, but you do have to put your money into it, take a leap of faith, it's a bit like playing roulette, you've got to be in it to win it, so you've got to take your chances." While genetic testing gives the donor-conceived the chance to "put themselves out there", the outcome of their search, similar to a round of roulette, cannot be predicted. While they might 'win' and find their donor, they have to try it first. In the following section, I will explore the feeling of "having to try" in more detail.

8.3 Having to try: Anonymity and inevitable choices

Similar to the intense scanning of others that people were drawn into (section 5.4), genetic testing emerged as something that many of my donor-conceived interlocutors felt they had to do: they felt that they had to at least try and find their donor and their donor siblings, and DNA testing was seen as the easiest way of finding someone. Genetic testing could be experienced as a way of *doing* at least *something* to find genetic relatives and "put yourself out there", which was also the main reason why people decided to join voluntary registers. While searching for genetic connections can be "comforting in terms of providing a sense of previously lost agency brought about by past experiences of an absence of kinship knowledge" (Klotz 2016: 51), DNA testing and scanning both emerged as practices that were not entirely agency-controlled. My interviewees generally felt compelled to make use of the commercial testing opportunities that were available to them, and often bought a test as soon they found out about genetic ancestry testing. Jessica Robertson, who had joined the DCR as soon as she was told about its existence (section 7.6), commented that she had ordered several DNA tests as soon as she had found out about them: "It was like, ok, they exist, I'm doing it." Not buying a test and not giving it a try was not an option for the vast majority of people that I interviewed. Their approach

to genetic testing bears interesting parallels to what anthropological research on reproductive technologies and especially IVF has shown. In the following section, I will focus on the work of two authors who explore why, especially for many women, not trying IVF is not an option (Franklin 1997), and why ending treatment can be difficult (Throsby 2004). I will use an example from my material to show that DNA testing, similar to IVF, could draw people in, and discuss how it was still possible for them to end their active search. Finally, I will address the criticism of those who argue that genetic testing is a threat to privacy, which was a concern voiced by only a few of the people that I talked to.

Sarah Franklin's study *Embodied Progress* (1997) was one of the first detailed accounts of the lived experiences of IVF.[30] "Having to try" was a central motif in all of the interviews Franklin conducted with women who were in the midst of treatment (1997: 102).[31] At the time of her research in the late 1980s, the average UK success rate for IVF was 8.6 percent (1997: 82). Franklin shows that while pursuing IVF can be seen as giving infertile women the possibility to pursue motherhood, it is also experienced as an inevitability: "If the procedure is seen as the only way to realise this desire, then there is no decision, no 'choice'; the answer is a foregone conclusion." (1997: 171) The women she interviewed felt compelled to leave nothing untried and wanted to have "the certainty of knowing they did everything possible to succeed" (1997: 173). However, "this is precisely the certainty that IVF takes away" (ibid.), and despite low success rates, women felt compelled to try *and keep trying*, as IVF offered them the hope of having a child. Deciding to stop treatment and "to abandon hope for success may have become much more difficult after 'living for the dream' from cycle to cycle, often over several years" (1997: 12).

In her study of what happens when treatment fails, Karen Throsby found that those who underwent IVF would frequently mention "[t]he need to have tried every possible means" (2004: 164) before ending treatment. However, "what actually constitutes 'doing everything' is frustratingly indeterminable" (ibid.).[32] Even though

30 The chapter entitled "'Having to try' and 'Having to choose': how IVF 'makes sense'" (Franklin 1997: 168–197) inspired the title of this section.

31 Franklin and Roberts (2006) have shown that a similar dynamic shapes the way people approach PGD. While having a child born free of a specific genetic disease might have motivated patients to start treatment, experiencing failure in the form of not being able to conceive is not entirely and permanently negative because "a child is not the only potentially positive outcome of PGD" (2006: 192). Instead, "satisfaction and a sense of shared achievement" (ibid.) can also derive "from having given PGD your best try, from those aspects of the technique that have succeeded (such as producing good embryos), or from being "free" to move on to something else" (ibid.).

32 Asserting that one has tried everything has several aspects to it: it refers to having tried everything that is not excessive and risky. It also indicates that patients accept that they are, at least to some degree, responsible for the outcome of a cycle and enables those who end

Throsby's research in the UK took place about a decade after Franklin's study, the failure rate for IVF was still high, with about 80 percent of all cycles not resulting in a live birth (2004: 7). Throsby found that "while there are well-trodden paths *into* IVF, the routes *out* of treatment are more obscure" (2004: 162, emphases in original). She argues that ending treatment can be a long process that might be imposed upon patients "as a result of financial limitations, health problems, age, or their partner's refusal to participate" (2004: 15). Once treatment has been stopped, women have "the task of creating, or at least imagining, a future different from the one on which their engagement with IVF was predicated" (2004: 185). While some found resolution around their inability to conceive, Throsby found that "the inability to imagine a positive future without children remained an apparently intractable barrier" (2004: 184) for others.

In my field, too, it sometimes happened that the desire and the need to find the anonymous donor was so great that people would keep on trying and trying. This was especially the case with Nadine Fuchs, whose time and work-intensive search for her donor I have described in the previous section. Searching for the donor, which was not only limited to buying DNA tests, seemed to have taken over her life, similar to the way in which IVF can become "a way of life" (Franklin 1997: 101). Interestingly, those who invested a lot of time in their search often emphasised that having a match was also a matter of luck, and not just down to hard work, with Elizabeth Chapman (section 8.2) stating that DNA testing was "a bit like playing roulette". Here too, a similarity with the way in which women make sense of IVF can be observed: "It is like a kind of gamble or roulette. Hence, on the one hand, IVF is sought out as an enabling technology, yet on the other hand it is perceived as subject to a kind of random element no amount of assistance can mitigate." (Franklin 1997: 177)

Unlike Nadine, who wanted to leave no stone unturned, most of my interlocutors approached their search and their use of genetic testing differently. But even those who told me that they were not desperate to know and who emphasised that they were not willing to take extreme measures mentioned they had taken a DNA test, which was oftentimes described as an "easy thing to do". Although they would sometimes point out that they would be fine without knowing, not buying a test was not an option for them. Especially my German interlocutors, who had no mandatory or voluntary registers that they could access, oftentimes told me that they ordered a test kit from FTDNA as soon as they had found out about the database via Spenderkinder's website and internal mailing list. As they mostly did not receive any information from the physicians and clinics they had contacted, they felt that this was their only chance to get information.

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treatment to demonstrate that they overcame obstacles and did not give up (Throsby 2004: 165–167).

The way in which trying could have its very own dynamic that would draw people in got particularly clear in the way in which Alexandra Gerstner described her experience with genetic testing. She was conceived in Germany in the mid-1970s, making her one of my oldest interviewees. When I interviewed her, Alexandra knew for about a year that she was donor-conceived. Already in her first email she had mentioned that she was still struggling with the consequences of this information. As she told me during the interview, her talents and character had never fitted in with her parents and their family business. Knowing that she was not able to follow in her father's footsteps had torn her apart in the past. She also mentioned that she looked very different from her parents and bore little resemblance to her sister, and she suspected that her sister had been conceived with the sperm from a different donor. Alexandra stated that she was relieved to know the truth about her origins and happy to finally be freed from the pressure of having to fit in. Her newfound freedom seemed to help with her autoimmune diseases, as her health started to improve after she found out that she was donor-conceived. Nevertheless, she was in tears during most of the interview, which clearly brought back painful memories. After I stopped recording, we talked for another two hours, and Alexandra seemed to be more at ease. I told her a bit more about my time in the UK, from where I had just returned, and Alexandra went on to mostly tell me about her friends' and relatives' experiences with infertility.

Somewhat to my surprise, her donor was not the person she was most interested in. Alexandra suspected that he had simply been "a happy student" (*ein fröhlicher Student*) who probably donated without really thinking about it. However, she was very curious about the women in the donor's family, whom she could only find by locating the donor first. Alexandra had already contacted and even visited the clinic where she had been conceived, but her visit had not yielded any concrete results. In the meantime, she had also done a DNA test. She described the process of ordering the test kit and sending it back to FTDNA's lab as something that had occurred almost automatically, with her executing the different steps as if she was controlled remotely:

> Alexandra Gerstner: "I'm very sceptical about disclosing information, and I'm very careful, and sending my genetic material to America would have been unthinkable before that, and I knew it [that she was donor-conceived] and heard about this Family Tree [she meant FTDNA] and did it immediately as if I was somehow a different person because I thought, 'Damn it, somehow you have no possibilities at all, you're simply doing this now', I don't know if it was the right thing to do. I stood there, I don't know, I somehow stood there at the post office and dropped off this parcel [with the test kit]. I don't know if I really understand what I was doing, but I didn't get any information. And I think that's unlikely, too."

Although taking the test had given her the opportunity to get active, receiving the results seemed to reinforce her feeling of being in a dead-end situation, as they did not reveal any useful information. However, Alexandra mentioned that she was not willing to "drag it around" *(rumschleppen)* her entire life and was therefore thinking about having a symbolic funeral for her anonymous donor. Similar to those who identify a new phase in their post-IVF life, which "contains the IVF and its failure within a discrete time period" (Throsby 2004: 181), Alexandra was hoping to leave her anonymous donor behind. She added that she would like her two sons to be at the funeral with her "because it's kind of about them too". Alexandra had mentioned earlier that she felt it was a pity that the anonymity of the donor deprived her sons of the opportunity to identify with their genetic grandfather: "Because you only really become a human through this identification, and I think it's a pity that my children don't have that opportunity." She had decided not to continue the search for her donor actively, but instead to trust that she would get the information she was supposed to receive: "Because that [an active search] doesn't get me any further and that doesn't make me healthier, or help the children [her sons] either, I think if I am allowed to find out something, then I will find it out." She thus evoked a future that, despite not being predictable, was organised in a specific way: even without an active search, she would find out what she was meant to find out. This approach enabled her to keep any fears about never being able to know at bay. Her belief bears similarities to the concept of fate that was frequently evoked by Throsby's interviewees (2004: 168). According to Throsby, asserting that there is "an unknowable, but directed, greater purpose offers a framework within which to accept the ending of treatment without writing off that treatment as futile" (2004: 170). The assertion of fate could justify both the choice to continue treatment and to end it (2004: 168–171).

For Alexandra, asserting that she would receive the information she was "allowed" to receive enabled her to remain moderately hopeful while not searching actively, and despite telling herself that she was probably not going to get any results. Alexandra did not explicitly refer to genetic testing when talking about her 'fate'. Commercial genetic testing, however, allows the donor-conceived to remain moderately, and reasonably, hopeful. As long as the donor-conceived do not delete their accounts, which none of my interlocutors had done, it is still possible that one day they will find a donor sibling or their donor. This allows them to simply wait until they get a match. While a one-time registration is sufficient for FTDNA and other databases, a new cycle must be started if one round of IVF does not lead to pregnancy and then birth. Since each cycle has to be paid for, and especially if the number of insurance or health authority funded cycles is limited, continuing to try and conceive via IVF might no longer be a financially feasible option at some

point.[33] I will elaborate on this difference and what it meant for those who had not found any relatives yet in more detail in the next section (8.4).

Whereas Alexandra usually had reservations about the disclosure of personal data, these reservations had been temporarily suspended when she found out that there was something she could do to try and find her donor. In fact, my interviewees rarely expressed concerns about the sharing of genetic information, even though I was told in Germany that some members of Spenderkinder were not comfortable sending their saliva samples to the US where the FTDNA lab is located. In the UK, Jessica Robertson suspected that more and more people would find out that they were donor-conceived, as genetic testing was getting more popular. She laughingly commented, "Maybe that's a little bit dodgy, companies with all of our DNA", with her laugh indicating that she was not really concerned about her genetic data being misused. This seemed to be different with Jade Foster from the UK, who had not yet bought a test kit:

> Amelie Baumann: "Have you ever thought about submitting your DNA to a genetic testing site?"
> Jade Foster: "I thought about it, but part of me feels weird about a corporation having access to my genetic material. You know, what are their ulterior motives, which I know is a little bit conspiracy-theorist, but the fact that this is you, that is the essence of you, and you're handing it over to a big anonymous corporation, and they've got *all* of the information about you. And they can do what they want, and that scares me a bit."

While rejecting DNA testing might be interpreted as a sign that genes are not considered important, an acknowledgement of the authority of genes did figure into her decision (see Gandsman 2009: 450 for a similar argument). She considered genetic data to be information that was not merely about her, but also constitutive of her. It should be noted that despite her belief in the importance of genetic data, Jade, as was the case for the majority of my interviewees, did not hold on to a geneticist idea of kinship. She remained close to her older sister from her father's first marriage, whom she had previously believed to be her genetic half-sister, and her sister's children whom she loved ("they are my world").

Whereas concerns about the sharing of genetic data were rarely expressed by my interviewees, genetic testing is viewed more critically elsewhere. Concerns

33 Interestingly, Throsby found that a "continued possibility of conception was a recurring theme in the interviews" (2004: 173). Even after the end of treatment, "the possibility technically remains" (2004: 174), although stories about others suddenly conceiving without any medical intervention "were generally approached with scepticism and annoyance" (ibid.). Instead of actively trying to get pregnant, it mostly meant that couples were simply not using any form of contraception (ibid.).

about the privacy of genetic information are rooted in debates about the Human Genome Project, a research project aimed at determining the complete sequence of the human genome that was initiated in 1990, and the emergence of population biobanks. These developments triggered concerns about genetic information potentially becoming a means for stigmatisation and discrimination, which in turn lead to the creation of "genetic privacy" (Knoppers 2010: 416) laws.[34] However, a 2016 review of how companies offering health and ancestry testing comply with guidelines formulated by governments and professional bodies found that "there have been only modest developments toward improvements in transparency about privacy risks, the fate of data, and secondary use of data over the past decade" (Laestadius et al. 2016: 518). The authors note, for example, that one-third of all companies did not require consent to use genetic data for research, which they interpret not only as a violation of official recommendations but also as "a continued blurring of the lines between consumers and research subjects" (ibid.). A study that looked at how companies offering testing in Canada communicate privacy information found that the information they included on their websites tended to address "aspects of privacy related to the web interface, rather than privacy implications of genetic testing, disclosing health information, and third parties gaining access to an individual's genetic information" (Christofides and O'Doherty 2016: 117). Companies have also been criticised for formulating their contracts in a way that does not give costumers sufficient control over their data. A lot of companies have variation clauses that allow them to significantly alter their terms and privacy policies. They might, for example, decide to share and sell genetic information despite initially having stated that they will not do so (Phillips 2017: 284).[35] For these reasons, it has been argued that in order to protect genetic privacy in countries where this is not yet the case, testing should be regulated by

34 At the same time, genetic health testing in particular is also interpreted as increasing the individual's privacy and as having the potential to "democratize health care by enabling individuals to make choices that maximize their own health" (Green and Farahany 2014: 287). Offering a more critical perspective as part of her analysis of genetic testing in the UK, Teresa Finlay argues that it "capitalizes on neoliberal policies that emphasize individual consumerism" (2017: 227). Responsibility for managing and monitoring health is increasingly devolved to individuals (ibid.). At the same time, the welfare state is being reduced, which leads "to wide disparities in the level and quality of care people receive" (Sakellariou and Rotarou 2017: 199(2)).

35 Privacy concerns have also been voiced concerning third party analysis offered by GEDmatch and other sites. A review of companies offering this kind of analysis found that they did not share or sell genetic data (Badalato et al. 2017). However, they tended to have "vague, nonspecific privacy policies, some risk of breach of privacy, and a lack of discussion of the risks associated with privacy breach" (Badalato et al. 2017: 1192).

state authorities and not by the companies themselves (Christofides and O'Doherty 2016: 120).

While the use of DNA tests can be a way to circumvent regulations, the companies providing these tests operate in a space that has so far largely evaded regulation. Considering the importance that my interviewees attached to managing who else knew about the circumstances of their conception (section 6.1), I found it surprising that genetic testing and the sharing of genetic data rarely elicited critical comments. The impression of having to try seemed to be so strong that concerns about privacy were pushed aside or did not even arise in the first place.

8.4 Waiting for DNA: More matches, more hope, more frustration?

While those who try IVF hope not only for conception but also for a parent-child relationship, my interviewees would oftentimes stress that for them, it was primarily about having the knowledge, and not about developing a relationship with the donor (see also section 3.5 on the "right to make a choice"). They were usually hoping for a closer connection with any donor siblings they might find. With DNA testing, a donor-conceived person might find not only a donor sibling but also the donor long after registration, without having to register and pay twice. This enables the donor-conceived to maintain a sense of hope without actively searching for a genetic relative. Those who have tried their luck with genetic testing can put an end to their active search because they have tried, similar to those who have experienced the failure of IVF, "everything that is reasonably, rather than literally, possible" (Throsby 2004: 165). Given the growth of DNA databases, hopes and expectations appear to be changing. For this reason, I will first discuss this growth and describe how there were more and more matches after I had conducted most of my interviews, which was particularly noticeable in Germany. Against this background, the question arises how people deal with the fact that they are still waiting for matches. Following on from the previous section, I will again draw on the work of Franklin (1997) and Throsby (2004) on IVF to discuss the specifics of waiting in my field. Finally, I will address the question of the extent to which the growth of DNA databases has the potential to change what it means to wait for DNA.

As there are more and more reports about more and more matches, those who do not have any matches yet seem to have every reason to stay hopeful. My impression that DNA testing started growing in popularity in 2017 is supported by the literature. Erlich et al. state that 15 million people had taken a test as of April 2018, "with about 7 million kits sold in 2017 alone" (2018: 690).[36] They argue that

36 As mentioned in the introduction of this chapter, Ancestry alone had about 20 million profiles on its database in May 2021.

"a genetic database needs to cover only 2 % of the target population to provide a third-cousin match to nearly any person" (ibid.).[37] Their prognosis projects an interesting scenario: even if not everyone had registered themselves, everyone would potentially become identifiable – at least for those registrants who choose to do more investigations on the basis of third-cousin matches. The rise of genetic testing seemed to be particularly noticeable in Germany, where Spenderkinder has been using FTDNA since late 2011. FTDNA was the first commercial database whose tests were available in Germany. I was told that prior to that, the association had thought long and hard about whether they should create their own register. However, the experiences of American and Australian donor-conceived activists who had in the past tried to set up a designated donor-conceived database, using the same testing system as the DCR (section 7.6), had eventually persuaded them to decide against that option. Given the uncertain nature of the test results yielded from STR tests, their international contacts decided to not continue with their project and recommended Spenderkinder to use FTDNA instead.

The first match between donor siblings was announced on the website in August 2013 (Spenderkinder 2013). Whereas the organisation had announced eight "half-sibling matches" (*Halbgeschwistertreffer*) by the time I started interviewing members in February 2017 (Spenderkinder 2016a), this number quickly started to rise afterwards. In 2017 alone, nine matches had been made, one more than in the first five years combined (Spenderkinder 2018b).[38] A large proportion of the members have discovered that they are related to someone else in the association. This was also interpreted as a sign that doctors probably used to work with a small number of donors who donated over a longer period, resulting in a relatively small number of large donor sibling groups. Meanwhile, new matches are no longer announced on the website. A person in charge of the organisation's homepage confirmed my guess that their growth and frequency had made it impossible to keep writing accompanying blog posts.

Besides, registering with several sites seems to have become a common practice, especially since test kits other than the one sold by FTDNA have become easily

37 According to Erlich et al., a database with three million Americans of European descent would be sufficient for this to happen in the US (2018: 690). They also argue that in view of "the exponential growth of consumer genomics […] such a database scale is foreseeable for some third-party websites [such as GEDmatch] in the near future" (ibid.).

38 When the twentieth match was announced in July 2018, the accompanying blog post announced that Spenderkinder would from now on count half-sibling groups instead of single matches (Spenderkinder 2018d). According to the blog post, the association had 18 sibling groups with up to seven members; just three months later, one of these groups had grown even further and had nine members in total (Spenderkinder 2018a). This again constitutes a growth compared to the biggest group at the time of my research, which consisted of five donor siblings.

available in Germany.[39] Ancestry, for example, had only become available in November 2018 (Weichert 2018: 4). In the past, those who wanted to buy additional tests from other companies had to order them through friends or acquaintances living abroad. The goal behind registering with several databases is to achieve the broadest possible distribution of one's DNA, thus increasing the chance of a match.[40] The increasing number of matches indicates that this strategy is indeed working for some members.

In 2019, reports started to emerge that the growth of DNA banks has actually slowed down, and, despite the impressive number of matches, is not as strong as predicted. For example, if Ancestry's growth had continued to be as steep as it had previously been, the database would have had over 20 million users in June 2019 instead of 'only' 15 million, at least according to a popular genealogy blog (DNA Geek 2019).[41] Reports on the subject cite market saturation and growing privacy concerns as possible reasons for this decline in growth (Farr 2019). However, these reports have not been reflected in media reports about the donor-conceived and genetic matching or in the discussions I had been able to follow online. The view that the growth of DNA databases will 'end' anonymity still seems to prevail.

Given the increasing number of 'success stories', one can easily get the impression that having a match has become merely a matter of time. This was in fact the guess of Jennifer Bunton, whom I interviewed prior to the 'blossoming' of DNA testing. By the time she did her first DNA test, she had known about the circumstances of her conception for about two decades. However, she had only found out by chance about the way in which genetic testing could be used to find relatives through an article she had seen on Facebook. Jennifer had immediately decided to order a test, "just because I realised that there are things that I can do to try and find my biological father and to see if I've got any siblings out there". She explained that she had always wanted to know (see also section 4.3). However, she had not known what to do prior to reading the article, which was about adoption and genetic testing. Jennifer had since then registered with the DCR and bought tests from Ancestry, 23andMe and FTDNA, which she commented with "I think I have covered all bases." Despite only having had results that she described as "useless,"

39 The blog posts that announced new matches usually described how and where a match had been made. These posts indicate that members were increasingly registering with multiple sites instead of only using FTDNA. I also learnt that some of my interviewees registered with at least one more database after I had already interviewed them.

40 This approach is also reflected in the expansion of Spenderkinder's website, which now contains information on how different tests can be combined (www.spenderkinder.de/-verwandtensuche/verwandtensuche-mit-hilfe-von-dna-datenbanken-und-weiterer-werkzeuge/, last accessed April 07, 2020). This guide was not yet available when I first started interviewing people in Germany in 2017.

41 In the meantime, Ancestry's database has reached (and surpassed) this number of profiles.

Jennifer seemed optimistic about her chances of having a close match in the future, commenting that "Ancestry just had a massive sale on" and, according to Jennifer, sold 250,000 tests in one weekend. She therefore believed that "it's just a waiting game. And just riding it out and seeing what comes back." Since she was certain that more and more people would undergo testing, Jennifer managed to remain hopeful as she waited for a match.

In their introduction to the edited volume *Ethnographies of Waiting* (Janeja and Bandak 2018), Andreas Bandak and Manpreet K. Janeja argue that "waiting as a phenomenon is an unstable object" (2018: 16). It may elicit a variety of reactions and "release diverse affects ranging from hope, enthusiasm and urgency to apathy, paralysis and lethargy" (ibid.). While waiting for more DNA and more matches did not seem to be stressful for Jennifer, the waiting involved in an IVF treatment can be extremely difficult for patients. Paradoxically, IVF and other technologies are commonly conceptualised as a means to put an end to the wait for a child and to the "tentative future, a future 'on hold'" (Franklin 1997: 135) created by the condition of infertility. In the UK, couples that meet the criteria for NHS-funded IVF treatment often have to wait years for their turn which can be "a further incentive to turn to the private sector, or to self-fund treatment in an NHS context" (Throsby 2004: 80). However, the waiting does not stop once a cycle has started. It is not until two weeks after the embryo transfer that a blood test is performed to determine whether pregnancy has occurred (Franklin 1997: 109). Each test needs to be approached with a "'balance' of hope and preparedness for failure" (Franklin 1997: 154). Throsby found that in the accounts of the waiting period prior to the blood test, "positive thinking and relaxation played an important role, drawing on the long tradition of assuming that women can influence the outcome of pregnancy by the force of their imagination or mood" (2004: 145). Women in particular often felt a great sense of responsibility following embryo transfer, with many of them taking the time before the pregnancy test off work in an attempt to manage stress (2004: 144). Franklin notes that for the women she interviewed, "a sense of having ones life taken over by the waiting, the worry, the activity and the stress was consistent" (1997: 115).

None of my research contacts spoke in detail about the time between sending back the test kit and receiving the results, which in the case of FTDNA takes four to six weeks. Only David Winkler from Germany briefly described how he had waited impatiently for his results to arrive. At the time of the interview (March 2017), there had only been a small number of half-sibling matches in Germany. Similar to the majority of my interviewees, David had ordered a test soon after he had found out about genetic testing and the way it could be repurposed by the donor-conceived:

> David Winkler: "I ordered this set from the US, which arrived, I waited until it finally arrived, did the test immediately and sent it away again, [laughs] and then

> waited again until the results were there. And then I got an email that the test was now processed and saved in the database, now the analysis is done, and then a few days later I got the analysis, [the message] that the results have now arrived. And again, I opened the website with heart palpitations and saw, as it is the case with the vast majority [of donor-conceived people], of course I had no direct close relatives [*Nahverwandtschaft*] and hundreds of female cousins, male cousins, fourth, fifth degree [laughs]. And with that the topic was over for me, and then I noticed in that moment how important it was or is for me to find half-siblings, because I told myself a hundred times in a sensible way that the probability to find someone there is low, but I'll register, and that's that. And when I saw the negative result, it pulled the rug from under my feet because I thought, this is the easiest and most convenient way to get to relatives, close relatives, that's over for now. But at the same time, I think it's good that something like that exists. It has been established for completely different purposes, but it's simply now [laughs] used by the association Spenderkinder for this purpose […] And I think it's great that there is such a thing, and I can only hope that all donor children [*Spenderkinder*] who somehow realise that there is such a thing also register."

Although David had tried to lower his expectations by acknowledging that the test might not have any useful results, he was nevertheless disappointed when the results came back and revealed that so far, no donor siblings were registered. It was this feeling of disappointment that made him realise how much he wanted to find his unknown relatives. Interestingly, David did not seem to consider his "convenient" registration with FTDNA to be part of his actual search. He wanted his parents to finally tell his brother about the circumstances of his conception because he felt that otherwise he would not be able to start his actual search. David told me that once his brother was informed, his "engagement" (*Auseinandersetzung*) with donor conception would enter a new "phase" because "then it's about the search for the father and about the search for half-siblings". David saw his media activities as a means to reach out to donor-conceived persons and motivate them to register with FTDNA (section 4.2). While the women in Throsby's study felt a strong sense of responsibility for successful implantation during the waiting period of an IVF treatment (2004: 144–145), David wanted to do his part to increase the chance for a match, both for him and others, even though (or rather because) his initial results had been 'useless'. He wanted to make sure that other donor-conceived persons also found out about genetic testing. For David, the time between his own registration, his first results and a possible match was not a "waiting game" (Jennifer Bunton) during which he could not do anything, but a time in which he had to remain active himself.

Those who had a weaker desire to know their donor and donor siblings, did not really expect to ever have a match, or had already found someone tended to choose

a more passive approach. For them, it was more a matter of having to wait and see. For example, Diana Kraft from Germany was of the opinion that she had exhausted all possibilities. She had not received any information from the doctor that had treated her mother, and her registration with FTDNA had not resulted in close matches. Diana was particularly interested in getting to know her donor siblings. Through her contact with other members of Spenderkinder, she had seen that the joy they felt when they got a match and made contact with a donor sibling was usually enormous. As mentioned earlier, I had interviewed very few people who already had a genetic match at the time of the interview (but see for example Sabrina Frey in section 5.3). However, the joy mentioned by Diana was also described to me in the interviews with those who had already found a donor sibling. Diana reasoned that "it's nice to meet someone else who has partly similar roots". Although she was very curious about her anonymous donor and what he had passed on to her, she emphasised that she did not want to turn the search for her donor into her "purpose in life" (*Lebensaufgabe*) because she was at peace with herself. Diana felt that there was nothing left for her to do and concluded she could "no longer actively search, you'll just have to see [*man muss halt schauen*]". She felt that she had done everything she could reasonably do. Waiting for the donor and donor siblings was not something that took over her life.

Similar to Alexandra Gerstner who was confident that she would find out whatever she was "allowed" to find out (section 8.3), Diana did not explicitly refer to genetic testing when talking about the end of her active search. Elizabeth Chapman, for her part, explicitly referred to DNA testing when talking about waiting for her donor siblings. Since Elizabeth herself was in her early 60s, she did not think her chances of finding someone were very high:

> Elizabeth Chapman: "I'm always hoping that I'll find a half-sibling. I mean that's why I'm there [on FTDNA], waiting, but I don't think they're going to turn up now. […] My father probably started donating 20 years before that [her birth]. I would have half-siblings who are in their 80s, and I don't think there's going to be many people in their 80s who are going to be on a computer on FamilyTreeDNA, so I don't think I'm going to be lucky."

Elizabeth knew that it was theoretically possible to get a match at any time and had commented earlier that despite not having had any luck yet, she could "get a match fairly soon". However, she did not want to put too much hope into her FTDNA account. Due to the presumably high age of her donor siblings, she did not think a match was very likely. In contrast, Sabrina Frey from Germany, who was in her mid-30s and had found several donor-conceived half-sisters right after registering with FTDNA (section 5.3), was optimistic about finding even more donor siblings. As there was a large age difference between her and her donor-conceived half-sisters, she assumed that they probably had a 'long-term' donor and

rather many donor siblings. While this was a rather unpleasant thought for others (section 7.5), Sabrina felt that this might increase her chances of having and finding donor siblings: "I just hope that they will find out at some point and start searching and then find us. I hope that some of them will get in touch with us. Maybe also some brothers [laughs], it's only sisters at the moment." Sabrina was aware that several factors had to come together for a new match to happen. Her donor siblings had to know about the circumstances of their conception, decide to start searching, and look in the right place. However, she seemed rather optimistic about this happening in the near future.

I conducted the majority of my interviews prior to the 'blossoming' of genetic testing, which Jennifer had predicted as early as 2016, and which seemed to be indicated in Sabrina's experience of immediately finding several donor siblings. Given the growth of DNA databases, with reports about its recent slowdown not yet being discussed by the donor-conceived, one can easily get the impression that it is only a matter of time until someone gets a match. In contrast, IVF still has a high propensity for failure. In the UK, the overall live birth rate was at 22 percent "per embryo transferred" in 2017 (HFEA 2019c). Although this represents an increase from the early days of IVF, a cycle is still more likely to fail than to result in a pregnancy and birth. In the case of genetic testing, there seems to be almost the presumption that having a match is more likely than not having one. While official registers and regulations seem to evoke fears of never being able to know, I would argue that genetic testing may fuel hopes that one will know at some point. 'Never' is in this case replaced by 'not yet'. However, I did start to wonder whether "useless results", as Jennifer had put it, would also cause feelings of frustration, especially since people were likely to be confronted with other people's 'success stories' rather frequently. If genetic testing seemingly works for most people, how does continued 'failure' feel for those who are still waiting for matches? Are they still hopeful and encouraged by the matches they have witnessed, or are they increasingly frustrated by their own personal 'not yet'? If the donor-conceived seem to have more and more reasons to stay hopeful, how do they feel if they still have to wait for DNA?

This crossed my mind especially after I had spoken to Elizabeth for the second time. Elizabeth herself had found her donor after our first encounter, having registered with another database. She had linked the matches she had had on there with the information she had already managed to find through researching on- and offline. Through combining information from different sources, she had been able to identify her donor who was not registered himself, and who had already died. Despite DNA testing having "blossomed", as she put it, she still had not succeeded in helping one of her donor-conceived friends whose accounts she managed. Elizabeth had previously told me that she was "desperate for her to have a close match". Her friend's experience was different not only from her own success but also from what she witnessed online in Facebook groups: people who had just

taken a test, discovered that they had an immediate close match, and thus learnt that they were donor-conceived, were now joining these groups every week. While more and more people seemed to get a match right after registering with a DNA database, her friend was still waiting to get a match despite having been registered for several years. This seemed to frustrate and confuse Elizabeth, and she could not understand why her friend's match list was simply not growing. Due to the timing of my research, which took place mostly before genetic testing seemed to 'take off' and then slow down again in terms of growth rate, my thoughts on these new hopes and frustrations are rather tentative. More ethnographic research is needed to better understand these developments.

8.5 Recapitulation

Commercial DNA tests, originally designed for ancestry research and as personalised health tests, are increasingly being used by the donor-conceived to find donor siblings and donors. By creating new ways of linking information that further blur the boundary between identifying and non-identifying information, genetic databases have changed how and when information can be accessed, and by whom. Often the type of testing they use is considered superior to the technology employed in voluntary registers and forensics, as it is said to measure the amount of shared DNA. Since algorithms do not distinguish between different connections that have the same amount of shared genetic material, those who take the test must carry out the exact determination themselves. However, DNA databases operate with a certain kinship terminology and use specific "relationship ranges" that determine how a particular relationship is to be defined. They are therefore still prescriptive and work with an understanding of kinship that is not universal. If there are no close matches, the donor-conceived might decide to engage in a more intensive infrastructuring of information and DNA, trying to connect the results they have from various databases with results of their offline and online searches.

While not everyone was willing or able to invest additional work, for the vast majority it was not an option to not even try a test. Many ordered one as soon as they heard of DNA testing and the way the databases could be used by the donor-conceived. Especially in Germany, where people had no access to mandatory or voluntary registers, and usually got little to no information from clinics, it was immediately clear to many that they had to order a test. For the donor-conceived, DNA testing has become a "hope technology", a term Franklin (1997) coined in her early study of IVF. While IVF is a technology the involuntary childless have to try because it gives them the chance to have a child, the hope it creates also makes it more difficult to end treatment. However, DNA testing and IVF differ with regards to the amount of ongoing involvement they demand from those who use these

technologies. With a DNA database, there is always the possibility that a search will be 'successful' without the donor-conceived having to start a new 'testing cycle' once they end their active search. When IVF fails, a new round of treatment has to be started, which at some point in time will force some patients to stop trying. While IVF still has relatively low success rates, the probability of a genetic match seemed to have increased dramatically during my research. Genetic databases have significantly more members than just a few years ago. More and more people seem to find their donor siblings and donors, which raises the question of how those who are still waiting for a match are dealing with this situation. The question of new or future sources of disappointment also arises in view of the slowed growth of DNA databases. Although their membership numbers have increased enormously since I began my research, they have not grown as much as was expected. However, this development has not yet been discussed by the donor-conceived, and is not mentioned in the reports on DNA testing and donor conception.