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LABOR LAW AND GENETIC DISCRIMINATION IN CHILE

Hugo Rojas[*]

I. INTRODUCTION

It is known that science and technology contribute to transform social relations and cultural processes in a radical and constant manner. In the same way, the rhythms and velocity with which adaptations and

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actualizations take place inside the legal system do not always coincide with the speed of scientific breakthrough.

Lately, we have witnessed a true revolution in bioscience, and many even predict that biotechnology and genetic engineering will allow us to completely transform our lives in the twenty-first century. The important questions that biomedic science raise, require a bigger relation between law and ethics. We are facing a critical moment in genetic and biotechnology development. Lawmakers, judges, authorities, and government officials should take seriously the task of answering the uneasiness raised by the possibilities of patenting genetic material, controlling data bases, preventing new ways of discrimination based on genetic information, and assuring people that certain pieces of information will be used with caution and kept protected for the person's well-being.[1]

In this document there are two issues that deserve to be explored with detail considering the actual social-technological dynamics: the consequences of the Human Genome Project in the worker's privacy and in the field of working place relationships and how the Chilean legal system will react to those challenges. The worker's privacy could be seriously affected if employers demand their employees to undergo studies or genetic exams at any level of the working relationship. Unless the lawmaker interferes and assures the proper respect for employees' privacy rights and medical information confidentiality, employers will have the power to ask employees (and future applicants) for (medical) information, and to sanction the arbitrary and/or discriminatory conduct presented in the labor relationships — *latu sensu* — including employees' genetic material.[2]

Giant leaps taken in DNA research suggest that it is only a matter of time until everyone has access to their own genetic material, after undergoing exams that will become cheaper and easier to perform with time. Nevertheless, it is evident that beyond one's particular interest in undertaking such exams, there will be other people or entities, like employers, insurance companies, family members, etc. that could manifest an interest in accessing said results. Moreover, there is a threat that groups or organizations in a position of power could invade employee privacy and demand that they undergo these genetic exams, without ensuring

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[1] *See generally* RUTH HUBBARD & ELIJAH WALD, EXPLODING THE GENE MYTH (1999) (explaining how genetic information is produced and manipulated by scientists, physicians, employers, insurance companies, educators, and law enforcers).

[2] In part, the research project *Privacy Rights and Health Protection in Chilean Labor Law* (Center for Legal Advanced Studies, Pontificia Universidad Católica de Santiago, sponsored by Fundación Científica y Tecnológica Asociación Chilena de Seguridad), aspires to resolve some of the legal doubts.

beforehand that these organizations do not use the results in ways that could cause social injustice and unfairness.

Those with concerns about new ways of preventing unfair labor discrimination say, for example, that genetic testing could allow employers to find out privileged information that would exceed, by far, the limits allowed by standard labor and constitutional law. Jennifer Krumm warns that genetic testing could allow employers to meddle into employees' health records, private lives, and even their personalities. Therefore, employees should not be kept under the actual rules of the market and, instead, it will be necessary to prevent any form of labor discrimination done on the basis of genetic information by punishing the offenders. If these measures are not taken, the future of labor relations could be severely impacted.[3] In contrast, other sectors of academia are of the opinion that absolutely prohibiting an employer or a third party from using any genetic information about a particular individual should be addressed by the legislature in order to balance both the privacy rights of the employees and the rights of employers to obtain relevant information that will yield the appropriate working environment.[4]

Therefore, it seems appropriate at this time to review the tone of the current parliamentary debate on the "Law Project about Clonation and Human Genome"[5] in connection with other initiatives or statutes that are relevant in determining, with clarity and precision, the limits to be set forth in labor relations when obtaining, protecting, and spreading workers' genetic information.

II. THE HUMAN GENOME PROJECT

In April 2003 one of the most important scientific projects to have ever been carried out in human history successfully finished with the mapping and sequencing of the human genome. The Human Genome Project (HGP) is the materialization from the international scientific consortium effort that began in 1990 between different organizations from the international

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[3] Jennifer Krumm, *Genetic Discrimination*, 23 J. LEGAL MED. 491 (2002); Anita Silvers & Michael Ashley Stein, *An Equality Paradigm for Preventing Genetic Discrimination*, 55 VAND. L. REV. 1341 (2002).

[4] Marisa Anne Pagnattaro, *Genetic Discrimination and the Workplace: Employee's Right to Privacy v. Employer's Need to Know*, 39 AM. BUS. L.J. 139 (2001).

[5] The original name of the Bill is Proyecto de Ley Sobre Investigación Científica en el ser Humano, su Genoma, Y Prohíbe la Clonación Humana," presented at the Senate on March 12, 1997 (Motion on Boletin N° 1993-11). For more information see República de Chile, Biblioteca del Congreso Nacional Web Site, *at* http://www.bcn.cl/portada.html (last visited Sept. 30, 2004).

community. Their task was to work in the decoding of human genetic information; that means, to decipher the three billion chemical base pairs that form each cell and identify the thirty to thirty-five thousand human genes. In addition, the HGP wants to further determine the sequences of other organisms that will contribute to the interpretation of the meaning of our DNA. This, in turn, will provide information on the genetic differences between individuals and their dispositions for developing diverse illnesses. This implies a series of secondary or complementary objectives, such as, improvement of available computing programs that will facilitate future research and commercial use of the human genome, and supervision of the ethical, legal and social concerns in relation with it.

Originally, the deadline for this research was fifteen years, but bioscience breakthroughs and competition in this area helped with the early completion of the decoding process. With all this information in the hands of scientists around the world, we see that the sequencing and mapping of the human genome will provide great opportunities and unprecedented resources in the development of new investigations and the possibility to reach new discoveries.

The "genome" is the term used by scientists when referring to the totality of the genes found in our chromosomes. More precisely, the genome is the complete genetic information present in the cells of all living beings. From the chemical point of view, the "deoxyribonucleic acid" (DNA) is the substance from which all genes are formed and the carrier of hereditary information (genetic code). The DNA chain consists of a double helix-shaped structure formed of repeated sequences of sugar-phosphate units, each of which binds a simple chemical structure: the nucleotide (more commonly called a base). There are four kinds of bases present in DNA: adenine, cytosine, guanine, and thymine.

Not only the environmental factors but also genetic information plays a significant role in the development of any disease. This is why it is so relevant that through scientific discoveries and the application of specific techniques doctors will be able to increase their knowledge as well as their abilities to diagnose illnesses, identify weaknesses or pathologies in particular genes, offer new medical treatments, and prevent manifestations of certain diseases.[6] It is known that human beings have thirty to thirty-five thousand genes, and that it is currently possible to know through one

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[6] *See* JAMES D. WATSON, DNA. THE SECRET OF LIFE (2003); Joel Zimbelman, *Technology Assessment, Ethics and Public Policy in Biotechnology: The Case of the Human Genome Project*, *in* CHANGING NATURE'S COURSE. THE ETHICAL CHALLENGE OF BIOTECHNOLOGY 91 (1996); Genomics and Its Impact on Science and Society: The Human Genome Project and Beyond, *available at* www.questia.com/PM.qst?a=o&d=98860229 (last visited Aug. 20, 2004).

experiment the way in which more than twelve thousand of those genes are expressed. As a matter of fact, the combination of computer science and genetics has diminished the amount of time necessary to get to know the results of any exam. In this way, it will be possible to identify more than four thousand diseases or pathologies, in their different developmental phases, including cases having the potential to develop one or more diseases in the future.

III. PROTECTION OF EMPLOYEES' GENETIC PRIVACY

The purpose of this section is to identify a series of challenges in labor relations and in the protection of workers' privacy. These challenges have given rise and are relevant when talking about breakthroughs of the HGP. On the one hand, it will be interesting to find out whether job applicants or employees can or cannot be subjected to genetic examinations. If they can be, it will be interesting to know whether these examinations will or will not be done periodically. On the other hand, a second controversy exists as to who will or should have access to said results. Furthermore, it would be appropriate to inquire if it is possible to avoid discriminatory workplace situations affecting people whose genetic data do not meet insurers' and employers' expectations. A fourth point of controversy has to do with the latest protection mechanisms currently in place that could be used by employees, according to existing legislation and international agreements signed and ratified by Chile.

It is understood that such controversies make sense if we assume that the use of genetic examinations in the workplace will increase in the future. If that were not to occur, the research done would lose its importance because it would lack the nexus with reality. Nevertheless, there is a point we have to consider: in years to come the possibilities that costs of genetic examinations will decrease, and thus, employers may be tempted to take advantage of said examinations under the pretext of higher productivity and economic success.

This is so, that through the genome analysis it is possible to reach a better knowledge of potential diseases, or factors affecting the development of such diseases, of an applicant or an actual employee. Through genetics it is now possible to foresee a person's current and future physical and psychological capabilities.

Genes inform us of almost anything, from our physical and psychological characteristics to the potential diseases that workers may develop in his/her future. Knowledge of this kind of genetic information by employers creates by itself a barrier for employees to be hired.

With all this specific genetic information, the employer has in his/her hands a powerful instrument to discriminate among potential applicants. Through this process, the employer will be left with the possibility of choosing from a pool of ideal candidates leaving aside the ones who presented genetic flaws in their examinations.[7]

IV. THE RIGHT TO PRIVACY

Samuel D. Warren's and Louis D. Brandeis's paper called "The Right to Privacy,"[8] is commonly referred to as the contemporary motivation for legal discussions regarding this "new" right — a concept which the American system has developed under the notion of privacy; that is, the individual's right to chose how much of his/her feelings, thoughts, and private life they are willing to share with others. In other words, the right to control the information about oneself. Under the civil law system a different approach takes place. Experts in this area have made the distinction between "*intimacy*" and "*privacy*." Those experts state that private life is what one has, in general terms, reserved for them; while "*intimacy*" is referred as those things that are absolutely reserved to one self, the most personal things.[9] "*Intimacy*" then, is a strict concept of individual dimension, while "*privacy*" is a concept enclosing "*intimacy*" and then expanding beyond it.[10] Based on these notions, one can argue that "*privacy*" is something more general than "*intimacy*." Furthermore, it has been stated that intimacy is a fundamental right that arises from the dignity of every individual, and as we have pointed out, by dignity we refer to "the spiritual moral value inherent to the person, that it is shown in the conscious responsible self-determination of their own life and that involves the hope of being respected by the rest of the people."[11]

If we say that intimacy enfolds a person's essence, what makes the person different from another, then we can argue that it can be conceived

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[7] *See* FERNANDO DE VICENTE PACHÉS, EL DERECHO DEL TRABAJADOR AL RESPETO DE SU INTIMIDAD 123-23 (1998).

[8] Samuel D. Warren & Louis D. Brandeis, *The Right to Privacy*, 4 HARV. L. REV. 193-219 (1890) (about the protection of privacy and establishment of legal limits to the press according to Common Law).

[9] LUCRECIO REBOLLO DELGADO, EL DERECHO FUNDAMENTAL A LA INTIMIDAD 51 (2000).

[10] *Id.* at 85.

[11] CONSTITUTIONAL COURT OF SPAIN, 53/1985 (argument 8).

in two dimensions: first, as a fundamental right (innate, subjective, public, absolute) to make decisions about one's own life, and second, the power to decide how much of that information we are willing to share with other people so as to avoid undesired intrusions — from both public authorities and other third parties. Therefore, it is necessary to question the meaning of that right when the holder is an employer. So far, there is no specific recognition of the right to genetic privacy, although it can be argued that it comes from the right to intimacy. From this perspective, the right to genetic privacy can be conceived as the absolute right of an individual to control their own genetic information.

V. GENETIC EXAMS IN THE WORKPLACE

From a simple blood test, for example, scientists are able to detect more than four thousand different diseases that originated from hereditary genetic mutations. The exams currently being used enable us to foresee the potential risks that a healthy person has in developing a specific disease.

An important element of the comparative jurisprudence has declared itself against any kind of employers' intervention in employees' health records. However, opposed to this radical position and carried away by a hectic and heartless utilitarianism, some authors proclaim that there are neither legal nor ethical limits to prevent employers from asking their workers to undergo different medical examinations necessary for the development of productivity. The essence is to find a true equilibrium that will allow the employee to assure their right to privacy, and at the same time guarantee the employer the possibility to assess specific aspects of workers' health to prevent, or reduce, job related risks and adopt the necessary measures to protect their health and safety as well as the health and safety of the rest of the population.

An example may clarify this point of view. In many activities, such as mines that are located at high altitudes in the Andes, workers are exposed to greater risks than to workers working at sea level. Because of this, the employer has the duty to look over the health and safety of their workers, by performing continuous medical and physical checkups in order to assess the workers' medical situations. These medical assessments are authorized by the workers in a contractual manner at the time of their employment, and follow the guidelines established by sanitary and hygiene regulations. It is common in high risk occupations for the employer to end any contractual obligation if employees do not abide by the rules. A related but distinct topic is whether the firing is justified, although it should be noted that in Chile the clause "*necesidades de la empresa*" (company's needs) is widely used and abused.

If no changes occur in the Chilean legislation, we believe that nothing will stop employers from imposing terms on their workers, like through a clause in their contracts, subjecting them to undergoing genetic examinations, under the rubric of health and security regulations. Furthermore, there is nothing to stop public authorities from demanding genetic examinations — affecting their right of intimacy — if and when it is done under the explicit attributions present in the constitution and the laws, relying on the greater good of the community, public health, general or national interest. The armed forces or those in charge of public transportation, for example, could be forced to submit to periodic medical examinations that reflect their actual and potential health situation, so as to diminish risks that might cause damage and/or human casualties.

However, the development of genetic examinations should be regulated with precision and this task should not be left in the hands of the employers or the authorities. There should not be any space for unjustified demands or to leave discriminatory abuses unpunished.

VI. THE ACCESS TO GENETIC INFORMATION

Another issue to consider is the access to genetic results once the examinations have been performed. In the first place, the interest in the genetic information lies in the person undergoing the examination as well as other people or organizations. It is clear that the person performing the examinations will have access to the information. Needless to say though, employers and insurance companies will be interested in that information. At the same time, from the family or social perspective, people closely related to the worker or with family ties feel authorized to access this genetic data. Moreover, the state may be interested in retrieving said genetic results, for example, when in need of specific evidence that will aid in solving a case or conflict.

In the midst of such potential interest, the question is then: who has the right to the information? Why? There is no doubt that the collected genetic information, apart from those keeping medical records, should be known by the patient. The basic principle in this matter is the patient's right to privacy which involves his or her choice to share or not to share his or her genetic data with other people and organizations. The employers —

considering future productivity and trying to stay competitive by keeping costs low — can express their interest in acquiring the largest amount of information about the employees' private, familial, genetic, social and professional life. It is evident that this conflict of interest occurs and will continue to happen in the future. Now, let us analyze the following scenarios: 1) Employers are able to use applicants' and/or employees' genetic information, for the purpose of profit maximization. Since medical costs for the treatment of diseases are somewhat predictable, the employer can evaluate whether or not to discriminate against an individual who has a higher probability of developing disease in the future. In accordance with this is the warning expressed by Jared Feldman and Richard Katz: "[t]he knowledge gained from genetic testing maximizes employer's projects because employees who suffer long illnesses incur large health insurance disbursements. As a result, employers incur higher insurance costs from the companies underwriting the employer's health insurance policies."[12] 2) In a situation in which a person receives a diagnosis revealing a genetic disorder, this information becomes part of his or her medical record, then, with the continuing expansion of databases and research systems, third parties, and especially insurance companies, will do everything in their power to have access to that information and, eventually may take measures that will affect the individual. For example, they may be able to limit their insurance coverage, health plans, or social programs. There is a probability that some workers may agree to share their medical records with their employers; nevertheless, lawmakers should draw specific limits to prevent said information from reaching third parties who have no relation to the employer. We agree with Tara Rachinski when she says that computing science explosion generated from HGP and other advances in biotechnology have been received with great interest by policy makers, due to the potential abuses that may take place when dealing with private or confidential genetic information.[13]

These ongoing issues go even further. They are part of a huge debate about professional and medical confidentiality. In facing such an increase in genetic manipulation, through both electronic and virtual transmission,

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[12] Jared Feldman & Richard Katz, *Genetic Testing & Discrimination in Employment: Recommending a Uniform Statutory Approach*, 19 HOFSTRA LAB. & EMP. L.J. 389 (2002).

[13] Tara Rachinsky, *Genetic Testing: Toward A Comprehensive Policy To Prevent Genetic Discrimination In The Workplace*, U. PA. J. LAB. & EMP. L. 584 (2000).

the right to privacy should be reinforced in our legal system by punishing the offenders and assuring the prompt handling of any possible damage arising from it. In other words, the legislator should establish which will be the authorized methods to gather such information and under what circumstances in order to punish any discriminatory behavior through the supervision and control of public authorities. If an employer spreads genetic information without the employee's authorization, for example, this action should rise to the level of a fundamental right violation of the individual's right to privacy, and as such, the employer would have to face the legal consequences of his or her acts.

VII. DISCRIMINATION AND GENOPHOBIA IN LABOR RELATIONS

The term "discrimination" refers to any form of contempt, distinction, exclusion, restriction, or preference done — with or without the intention — by a person, group, or institution, based on race, color, religious beliefs, descendants, ethnicity, sexual preference, genetic information, or any other similar characteristic that may overturn or impinge the recognition of equal terms of an individual's basic human rights not only in the political, but also in the social, economical, and cultural areas.[14]

For the purpose of this Article, "genetic discrimination" refers to the kind of discrimination resulting from a damaging or arbitrary act towards an individual's genotype. When adding the term "labor" in this subcategory, we do so to reflect the fact that genetic discrimination can occur in any social sphere, at any time, including job or labor market relations.

Additions to the intellectual framework should be left in the hands of the legislature, lawyers, and judges, because we are referring to issues that are more than mere literary abstracts; we are talking about dynamic, changing, and multidimensional notions.

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[14] *See* MINISTERIO SECRETARÍA GENERAL DE GOBIERNO. BASES GENERALES DEL PLAN NACIONAL PARA SUPERAR LA DISCRIMINACIÓN EN CHILE 2001-2006 (Programa Tolerancia y No Discriminación, Santiago 2000), at 14.

VIII. MECHANISMS TO PROTECT EMPLOYEES' PRIVACY

From a constitutional point of view, the main rules can be found in chapter one of the Chilean Constitution.[15] There are two relevant articles in this chapter that can be used to protect the employee's right to privacy. Article 1.1 establishes that all people are born free with equal rights and dignity. This should be understood as one of the main rules that humanity has followed since modern times, being the basic idea of the political order and a minimum standard that cannot be trespassed by the government or others. So any damage claim raised by an employee can be brought under this rule in a court of law. Furthermore, Article 5 of the Constitution, modified in 1989, clearly establishes that the sovereign's right to intrude in people's lives is limited by the essential rights that arise from human nature — according to the international instruments ratified by Chile — including the dignity and privacy of every individual.

Equality before the law is recognized as one of the main constitutional guarantees mentioned in chapter 3 of the Constitution, and must be interpreted taking into consideration Article 19 number 16.3 (prohibiting any discriminatory act that is not based in personal capacity, with the exception of specific circumstances when nationality or age are required). Furthermore, constitutional guarantees of individual freedoms, and the rights to physical and moral integrity, privacy, and honor are hierarchically superior in the normative pyramid, so any employee could complain against any genophobic behavior or look for relief if genetic discrimination has been proved in the workplace.

A proper constitutional interpretation that is both pro-worker and respectful of the most elemental human rights is possible and can be useful in the Chilean legal culture as a starting point. However, it must be accompanied by reasoned jurisprudence and doctrine in labor law. In the concrete area of labor law, the Labor Code protects and prevents discrimination of any kind to employees.[16] It is well known that labor laws seek to compensate the disequilibrium between the employer and the employee, mainly because of the imbalance of negotiation power. In fact, and as stated by Fernando de Vicente, "the exercise of the employer's managerial skills constitute a real threat to the recognition of the workers' fundamental rights, and above all, those rights the worker has as a person

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[15] CHILEAN CONST. 1980.

[16] Labor Code arts. 2, 5.1.

and as a citizen".[17] However, and as later discussed, those rules are not enough to protect employees from pressures employers place on them to report their genetic information, so it is necessary to modify the Labor Code to be more specific in such terms.

In summary, (1) there are currently no legal obstacles impeding employers from requesting genetic information of their employees without their authorization; (2) the constitutional law sphere represents an enormous potential to solve conflicts arising from advances in biomedical sciences, and to protect the workers' constitutional and human rights that could be affected by labor relations; (3) nevertheless, it would be appropriate to shape and design a proper legal framework in order to protect the employees' genetic privacy and avoid any labor discrimination that may arise.

IX. THE LAW PROJECT ABOUT CLONATION AND HUMAN GENOME

There is currently a bill in the Chilean Congress prohibiting scientific research on human cloning. The origin of this bill can be found among the senators of the Christian Democrat party, Mariano Ruiz-Esquide, Juan Hamilton, Sergio Páez, Andrés Zaldívar and Nicolás Díaz. The proceedings started on March 12, 1997, and it is still being discussed in the Congress.

In its first phase, the bill was revised and corrected, and after much discussion by prominent researchers and scientists, the First Report of the Commission of Health was born (Senate, July 11, 2000). The document was unanimously approved by the members of that Commission — Senators Carlos Bombal, Mario Ríos, Mariano Ruiz-Esquide, José Antonio Viera-Gallo, and Enrique Zurita — and then it was sent to the Senate for its revision. The text had eight chapters and thirty articles. According to the Senate report, the main objectives of the bill were: (1) to set a judicial framework for scientific and genetic research in humans, gene therapy, and the human genome; (2) to prohibit human cloning; and (3) to create a National Commission on Bioethics.

On March 2, 2001, the Second Report of the Health Commission was presented. At that time, the same objectives were reiterated and, in regards to its structure, it was modified to twenty-three articles (eliminating the idea of dividing the document in chapters). Additional to the participation

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[17] PACHÉS, *supra* note 7, at 49.

of the already mentioned senators, other important personalities worked in this commission as well. Some of these personalities were Senators Fernando Cordero, Michele Bachelet (Minister of Public Health at that time), Charlotte Bouësseau, Danae Frings and Adriana Maturana.

The extent of the topics referred to in the Bill is too wide. The possibility to discuss every topic before the Bill is approved is very small. From the content of the Health Commission's sessions and from other reports prepared up to date, the topics raising more debates are: (1) the composition and attributions of the proposed Bioethics National Commission; (2) the prohibition of human cloning; and (3) the freedom to do scientific research.

In regards to genetic discrimination in the workplace, the topic of genophobia has not been properly addressed except in specific situations or in reference to international documents where the topic had been previously brought up before the proceedings began. The latter can be observed if one reviews the content of the Commission sessions, where labor matters are mentioned with much generality and vagueness. One reason for this may be that genophobia is not the specialists' priorities. Nevertheless, it is not clear what mechanisms the employees will have to protect and defend their rights against possible abuses from their employers. Therefore, it is the right time for the public to intervene to try to influence and correct any mistakes going on in these discussions. If the Labor Code is not modified, it is clear that genetic discrimination will increase.

Article 1 of the Bill points out that an individual's life, physical and psychological integrity, as well as their dignity and genetic identity should be protected, especially in cases like scientific research, including its applications. Two articles of the Bill deserve special attention since they are closely related to our previous discussion.

Article 4: It is forbidden in any way to discriminate based on genetic information. Article 13: The genetic information of an individual is confidential except when revealed by the person or authorized by a judicial order, all of this without interfering with professional secrecy norms.

On the one hand, there is no doubt that the discussion here presented is not going to solve many of the problems and challenges raised by the HGP project. On the other hand, there is no clarity about the sanctions the project establishes. The only thing we can salvage from this can be found in articles 14, 15 and 21 of the Bill:

Article 14: The gathering, storage, treatment and spreading of genetic information should be adapted to the regulations of the law N° 19.628, regarding personal data protection. Article 15: It is forbidden to solicit, receive, possess, and use genetic information about a specific and identifiable person, as well as investigations as to whether a person has undergone a genetic examination, except in those cases where there is legal authorization.

These prohibitions do not affect the gathering and processing of genetic information when such information has statistical and no nominative purpose.

Article 21.1: Those who violate an individual's confidentiality to their genetic information, with the exceptions mentioned in article 13, will suffer the penalties established in article 247 of the Penal Code.

This Bill cannot be analyzed in isolation. There exists a strong relation with another bill currently being discussed in the Congress. The Law Project about Patients' Rights[18] includes regulations that could be used by employees to protect the information about medical and genetic exams that employers and/or insurance companies may impose and/or know. Then, articles 8, 11, and 12 of this Bill are of great importance.

> Art. 8. Every patient has the right to be informed about his/her health. This right includes:
> 1. The right to be thoroughly and truthfully informed about his/her diagnosis, treatment, and therapy. This information must be given periodically, written and up to date . . . .
> 4. The right to have a complete and understandable medical record that includes the patient's personal information, the doctor in charge of his/her case, health system, kind of medical attention, diagnosis, treatment, evolution, proceedings and performed examinations.
> 5. The right to have access and a copy of the medical record.

Article 11: Every patient owns all of his/her information that has been obtained for the purpose of any therapy. This right includes: 1) The property right of the medical record; 2) The property right of laboratory exams; and 3) The property right over all official documentation about the patient's health condition, diagnosis, treatments, and studies.

Article 12: Every patient has the right to privacy and confidentiality regarding his/her health information. The institutions having this information must always respect this right, unless a judicial resolution

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[18] The Law Project About Patient's Rights, Message N° 038-344.

orders the contrary. This right includes: 1) The right to personal privacy; 2) The right of confidentiality about diseases, diagnoses, treatments or anything else related with his/her health condition; 3) The right of confidentiality of his/her medical record/history; 4) The right to refuse to discuss or give information to people other than those treating you; and 5) The right to have your medical record read only by those involved in your treatment or in charge of revising its quality.

Despite the two proposals presented, which involve advances and changes in the legal system according to scientific and technological activities, the rights of property, confidentiality, identity, and dignity of the employees are not being properly safeguarded. It is feasible to think that the levels of genetic discrimination in labor relations will increase beyond all known limits in Chile's history, because there is nothing stopping employers from asking an applicant or an employee the results of their genetic examinations. Unless there is direct intervention from the legislators, it will be impossible to stop pressures from insurance companies on employers to share said genetic or medical information.

In summary, in the ambit of labor relations, the suggested privacy and property of genetic information and medical records in general, may be reduced to a declaration of principles or good intentions. This is so since the owners of that information could freely share it with their employer, and the latter could do the same with insurance companies without fearing any consequences of their disclosure which could, in the end, discriminate against the worker.

It would certainly be beneficial for the country's economy and its development if along with employees' associations, insurance companies and employers' organizations would take part in the task of establishing norms that comply with the highest standards, not only as a sign of equality and social growth, but also as a showing of interest in human rights and the dignity of all Chilean citizens.

In facing this critical situation, two basic proposals are being set forth to advance the difficult mission of building a country in which justice, transparency, solidarity, equal opportunities, and the fight against discrimination are its ultimate goals. The proposals are the following: (1) intervention in the current parliamentary debate to introduce the issue of labor relations and potential discrimination that may arise so as to set the limits on the rights and duties of the employees, employers, and insurance companies; and (2) to revise the contributions in this area arising from international law and comparative experiences.

As to the latter, we should keep in mind that there have been advances in the international community that have influenced the laws of different countries. For further reading in this matter, the following international documents are of great interest: "Nuremberg Code,"[19] "Helsinski Declaration,"[20] "Human Genome and Human Rights Universal Declaration,"[21] "International Ethical Standards for Biomedical Research Involving Human Subjects,"[22] prepared by the International Organization of Medical Sciences (CIOMS) in collaboration with the World Health Organization (WHO), "International Ethical Standards for Biomedical Research Involving Human Subjects,"[23] prepared by the CIOMS in collaboration with the WHO, "The European Convention for the Protection of Human Rights and the Dignity of the Human Being with Respect to the Applications of Biology and Medicine: Human Rights and Biomedical Convention,"[24] and its additional protocol which prohibits human cloning,[25] "Ibero-Latinoamerican Declaration on the Law, Bioethics and the Human Genome."[26]

X. FINAL COMMENTS

The HGP is the result of thirteen years of collective effort and research that has involved different countries and organizations, which gave billions of dollars to fulfill the main objectives presented: identify thirty to thirty-

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[19] Nuremberg Code from *Trials of War Criminals Before the Nuremberg Military Tribunals Under Control Council Law No. 10*, Nuremberg, Oct. 1946-Apr. 1949, Washington D.C.: U.S.G.P.O., 1949-1953, *available at* http://www.ushmm.org/research/doctors/Nuremberg_Code.htm (last visited Nov. 15, 2004).

[20] Helsinski Declaration, 18ª World Medical Assembly, 1964, ratified in 1975, 1983 y 1989.

[21] Human Genome and Human Rights Universal Declaration, UNESCO, Nov. 11, 1997, ratified by the U.N. General Assembly Dec. 1998.

[22] International Ethical Guidelines for Biomedical Research Involving Human Subjects (1993), *available at* http://www.codex.uu.se/texts/international.html (last visited Nov. 15, 2004).

[23] International Ethical Guidelines for Biomedical Research Involving Human Subjects (2002), *available at* http://www.cioms.ch/guidelines_nov_2002_blurb.htm (last visited Nov. 15, 2004).

[24] The European Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Applications of Biology and Medicine: Convention on Human Rights and Biomedicine (1997).

[25] The Protocol of the European Convention for the Protection of Human Rights and the Dignity of the Human Being with Respect to the Applications of Biology and Medicine: Human Rights and Biomedical Convention (1998).

[26] Ibero-Latinoamerican Declaration on the Law, Bioethics and the Human Geonoma (1996, revised in 1998 and 2001).

five thousand genes in the DNA of human beings and to determine the sequences of the three billion chemical pairs that form DNA. To reach the previous goals there has been a close collaboration between the different areas of nature's sciences and the development in management information systems. This project also considered topics on ethics, law, and the social sciences that could arise as the Book of Life was revealed. As it has been illustrated throughout this Article, society has a great opportunity to take constructive advantages from the contributions accomplished by contemporary genetic studies. Such contributions make it possible to improve the quality of life of the population, although it should be made aware the potential risks from the improper use of this kind of information. Therefore, we must demand that the judicial system carry out its normative mission in favor of social peace and the well-being of its citizens. The previous discussion is nothing more than the manifestation of the two basic principles already mentioned in this Article: (a) "science is subjected to a constant process of transformation, which is quicker than others involved in our culture, and that keeps evolving into a more technical and complex one,"[27] and (b) the technological dynamism is diminishing our capacity of control, affecting both people's privacy and intimacy.

The fact that in Chile we have not yet approved any specific regulation punishing genetic discrimination in social relations or circumstances — including the labor field — is very worrisome. Such regulation is necessary to prohibit human cloning and to set limits on scientific research connected with the human genome. It has been five years since the five previously mentioned senators presented the Bill, and Chile still lacks any specific regulation.

In facing the lack of approval of the aforementioned regulation, it has been suggested that there needs to be a revision of the steps taken in the international community in regards to this matter. As it is known, the 1980s Constitutional reform of article 5, after the 1989 plebiscite, permitted the introduction of international instruments in the Chilean legal system with the possibility of being invoked in any court if any conflict were to arise.

A systematic interpretation of constitutional norms and labor rules enacted in Chile offers a huge potential to solve controversies that might come up from scientific and technological advances in biology. Issues that may take place involve those related with the promotion, protection and defense of civil rights, prohibiting conduct or threats of genetic

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[27] *See* JANET BROWNE ET AL., DICCIONARIO DE LA HISTORIA DE LA CIENCIA 11 (1986).

discrimination that could affect the honor, integrity, privacy, and dignity of an employee in any moment during the labor relation. In short, there are enough arguments to prevent the demands from employers and insurance companies to obtain access to genetic information in the absence of employees' specific authorization.

Since the aforementioned argument can be considered by some to be insufficient, and if we take into consideration the difficulties posed by the progressive invasion to our privacy by those in control of the new technologies and social powers, two alternative ways to confront this issue come up. On the one hand, we can adapt to the ever changing technological systems, databases, and electronic possibilities.[28] On the other hand, we can question the possibilities to safeguard our privacy taking into consideration laws that regulate our behaviors and social relations.

Assuming the latter position, and by securing specific limitations, it is fundamental to secure both the approval of the Bills currently under discussion in the Congress, as well as their corrections in regards to the punishment to be applied to those using genetic information to discriminate.

Genetic identity can only be understood as a key element of our privacy and dignity as human beings. If we do not do so and prevent discriminatory actions committed by employers, insurance companies, and others, the social effects could be disastrous. The Chilean legal response to these issues has been slow. Nevertheless, there is still time to remedy this situation. The proper limits should be set so as to create equilibrium between the employee's right to privacy and the employer's right to said information. Employees and applicants should be aware of the objectives sought by employers when undergoing genetic examinations. In other words, they should know in detail what is going to be evaluated and the consequences for their jobs. Those employees able to perform their jobs, and whose health is not a risk factor, should have the freedom to apply and develop in those jobs where he or she meets the performance standards required.[29] Measures in that direction could alleviate the fear arising from the misuse of genetic examinations. In any case, the information should only be used in a positive and constructive manner, and under no circumstances, to work against the worker in any kind of discriminatory situation.

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[28] *See* Amitai Etzioni, *Why Fear Date Rape?*, USA TODAY, May 20, 1996, at A14.

[29] Pagnattaro, *supra* note 4, at 183.