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REPORT ON MERITS

MARTINA REBECA VERA ROJAS CHILE

Approved by the Commission at its session No. XX held on April XX, 2018 $169^{\rm th}$ Regular Period of Sessions

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REPORT No. XX/18 CASE 13.039

MERITS MARTINA REBECA VERA ROJAS CHILE¹ DATE

I. SUMMARY

- 1. On November 4, 2011, the Inter-American Commission on Human Rights (hereinafter "the Inter-American Commission," "the Commission," or "the IACHR") received a petition lodged by Karinna Fernández Neira, Boris Paredes Bustos, Carolina Andrea del Pilar Rojas Farías, and Ramiro Álvaro Vera Luza (hereinafter "the petitioners")² alleging the international responsibility of the Republic of Chile (hereinafter "the Chilean State," "the State," or "Chile") to the detriment of Martina Rebeca Vera Rojas; her mother, Carolina Andrea del Pilar Rojas Faría; and her father, Ramiro Álvaro Vera Luza.
- 2. On November 4, 2016, the Commission adopted Report on Admissibility No. $44/16.^3$ On November 7, 2016, the Commission notified the parties of that report and placed itself at their disposal with a view to reaching a friendly settlement. The parties were afforded the regulation time limits to present additional observations as to merits. All information received was duly relayed between the parties.
- 3. The petitioners alleged that the State failed to fulfill its international obligations with regard to the life and integrity of Martina—a child diagnosed with the Leigh's syndrome—by allowing and judicially validating the unilateral and arbitrary termination of the in-home care (*hospitalización domiciliaria*) regime by her health insurer, a service that is essential for the survival of people with this syndrome. They indicated that the Supreme Court of Justice (hereinafter "the CSJ") ruled in favor of the health care provider without taking into account its special position of guarantor with respect to the rights of children and persons with disabilities or the social rights of the alleged victim. They also alleged that the facts are framed by a context of lack of regulation in matters of health care that is incompatible with the American Convention.
- 4. The State argues that it is bears no responsibility for the aforementioned violations, given that the harm to the life and integrity of the alleged victim was caused by her degenerative illness and not by a State agent. It indicated that health insurers are regulated and supervised by the State in a way that guaranteed the access of the girl Martina to the appropriate treatment. It said that despite the negative judgment issued by the CSJ, the Superintendency of Health ordered the health insurer to maintain the inhome care, so that life, integrity, and health were safeguarded in keeping with its position as special guarantor of the rights of the child, as well as ensuring the right to judicial protection.
- 5. Based on the findings of fact and law, the Inter-American Commission concluded that the State is responsible for the violation of Articles 4(1) (right to life), 5(1) (right to humane treatment), 19 (rights of the child)), 26 (economic, social, and cultural rights); and 8(1) and 25(1) (rights to a fair trial and judicial protection) of the American Convention on Human Rights (hereinafter "the American Convention" or "the Convention"), in relation to the obligations established in Articles 1(1) and 2 of the same instrument. The Commission made appropriate recommendations.

^{1.} Pursuant to Article 17(2) of the Rules of Procedure of the IACHR, Commissioner Antonia Urrejola Noguera, a Chilean national, did not participate in the discussion or decision in the present case.

^{2.} On April 14, 2017, the petitioner Fernández resigned her representation of the case. On the same day, lawyer Magdalena Garcés was designated as petitioner.

^{3.} IACHR, Report No. 44/16, Case 13.039, Martina Rebecca Vera Rojas (Chile), November 11, 2016. The petition was declared admissible in relation to Articles 4, 5, 8, 19, 25, and 26 of the American Convention. In addition, the Commission declared the petition inadmissible with regard to Articles 11 and 17 of the same instrument.

^{4.} The petitioners initiated the processing of a precautionary measure (PM 390-11) on October 14, 2011. The State submitted its reply and indicated the judicial processes available to the alleged victim in special arbitration proceedings. The processing of the precautionary measure was closed on April 2, 2013.

II. SUBMISSIONS OF THE PARTIES

A. The Petitioners

- 6. The petitioners said that Martina Rebecca Vera Rojas was diagnosed with Leigh's syndrome in 2007, when she was eight months old. They reported that at that time the family had health insurance coverage provided by MasVida S.A., a health insurance institution (*Institución de Salud Previsional*) (hereinafter "the Isapre") that included special coverage for catastrophic diseases (hereinafter "CAEC" for the Spanish, *Cobertura Adicional para Enfermedades Catastróficas*). They said that once the CAEC was activated, the alleged victim was included in the in-home care regime (*régimen de hospitalización domiciliaria*) (hereinafter "RHD") necessary for her condition. They added that on October 13, 2010, the Isapre, on the basis of a regulatory instrument of an administrative nature, withdrew the RHD on the premise that the alleged victim was no longer eligible for it because the condition was reclassified as chronic whose coverage was excluded.
- 7. According to the petitioners, the father and mother of the alleged victim brought an action for protection that eventually reached the CSJ, which overturned the decision at first instance and ruled on May 9, 2011, that the withdrawal of the RHD was lawful, as a result of which the regime was terminated that same day. They added that in December 2011, the family initiated an arbitration process before the Superintendency of Health (hereinafter "the Superintendency"), which ruled in favor of the alleged victim on August 27, 2012. The petitioners indicated that since the reinstatement of the RHD, the life of the family has become "a continuous struggle to ensure that their daughter receives the service that keeps her alive," given that periodically they have to institute proceedings to avert the termination of health care services.
- 8. They alleged that by validating through the CSJ the decision of the Isapre arbitrarily and without legal justification to withdraw the RHD, the State violated the rights to life, humane treatment, and health of Martina Vera Rojas, in addition to its obligation to adopt special measures for her as a child with a disability. They also held that the design of the health care system, susceptible as it is to arbitrary decisions and insufficiently regulated, created a problem of access to health care services by the alleged victim that is attributable to Chile. They reiterated that this lack of access for the girl Martina to certain health care procedures as a patient with Leigh's syndrome, exposed her to a serious risk to her life and integrity.
- 9. They said that the State violated the right to integrity of the mother and father of the alleged victim since, by accepting the removal of their daughter from RHD, it caused them suffering and chronic post-traumatic stress, due to the uncertainty surrounding the survival of the girl because of her lack of access to treatment.
- 10. It indicated that the State, by virtue of the ruling of the CSJ, failed to act with due diligence within a reasonable time, that the reasoning provided in the judicial decision failed to take account of the alleged victim's status as a child, and that during the proceedings before the Court they were unable to present arguments since that judicial instance does not contemplate that possibility. They noted that the guarantee of impartiality was violated because the composition of the Court included an alternate associate justice (abogado integrante) with a conflict of interest in favor of the Isapre. Therefore, they argued that the rights to a fair trial judicial and judicial protection were violated.
- 11. They claimed that Chile has violated its obligation to progressively develop the right to health by failing to ensure that, under the extended privatized scheme, providers adjust their rules and practices in line with domestic and international standards in order to ensure the right to health.
- 12. They highlighted the existence of a context in which access to health services is characterized by a downgrading of social rights such as the right to health and a lack of regulatory alignment with international standards in that area. They claimed that access to health care is determined by the bottom line of Isapres, which generates situations of abuse and unilateral changes in contractual conditions that are neither controlled nor regulated by the State, generating an excessive burden on patients who are forced to contend with legal proceedings against the service providers.

13. The Commission notes that the petitioners alleged violation of the right to family. Since those arguments concern a claim that has been declared inadmissible, the Commission will not consider them in its analysis of the merits of this case.

B. The State

- 14. The State denied the alleged violations of the rights to life and humane treatment of Martina Vera Rojas, given that her condition is the result of a disease that is not attributable to it. Likewise, it indicated that it respected and guaranteed the health of the alleged victim, since the State has standards and plans for the regulation and oversight of health insurers, which included the creation of CAEC itself. It said that the classification of a disease as "chronic" falls to the Isapre and that, in the event of a disagreement, there are avenues for challenging decisions before the Superintendency or the regular courts.
- 15. It argued that the petitioner did not explicitly state which rule adopted by the State is contrary to the Convention, so there are no grounds for alleging a violation of the duty to adopt provisions in relation to the rights to life and humane treatment. In this regard, the State indicated "that it has developed both legislation and an institutional framework for the observance and assurance of protection for children and adolescents."
- 16. It pointed out that it ensured the right to justice for the purpose of challenging the decisions of the Isapres through the arbitration process before the Superintendency of Health, which affords the opportunity to present evidences as well as recourse to review at second instance. It added that even though the action for protection in the instant case produced an adverse result, the activation of that jurisdiction did not extinguish the alleged victim's recourse to the Superintendency, which ultimately upheld her claim.
- 17. The State pointed out that Chile has made clear its express will not to grant powers to international organizations in relation to economic, social and cultural rights. Likewise, it indicated that there is no consent in the inter-American system for the litigation of cases in relation to the right to health and the right to social security, and that the argument of the "indivisibility of human rights" is not enough to assert violations of the right to health. It concluded by noting that Chile "supports the justiciability of economic, social, and cultural rights on the basis of their connection with civil and political rights, but does not recognize the jurisdiction of the protection bodies of the IAHRS to declare violations of Article 26 of the American Convention directly."
- 18. It argued that the development of the Chilean health care system "has been progressive and constant, as can be verified by various measures adopted in relation to the following: (i) infrastructure; (ii) coverage and rights of users of the health system; and (iii) budget," and that its health care system is among the most efficient in the world. It reiterated the different bodies, laws and policies related to the health system as a whole and mentioned the "State's will to progressively guarantee the right to health through legislative measures that ensure the delivery of health care in a timely manner and without discrimination to all persons residing in the national territory, in accordance with international treaties that have been ratified and are in force."It pointed out the instruments and institutions that it considers are part of its national health care policy and mentioned that in terms of its public aspect, the Chilean health care system has undergone progressive and permanent development through measures related to infrastructure, coverage and the rights of users of the health care system and budget. It also noted that since the 2005 health reform, Law 19.966 on Explicit Health Guarantees (CAEC-GES) has been adopted, as has Law 20.584, which governs rights and duties regarding access to information on people's clinical situation. Additionally, the State also pointed out that there is a Plan on Universal Access to Explicit Health Guarantees (AUGE) that establishes a group of diseases that all insurance must cover, a Financial Protection System for high-cost diagnoses and treatments, as well as the adoption of quality standards for health care providers, among other measures to improve health care for its population.

III. FINDINGS OF FACT

A. Background

- 19. According to the information provided by the parties, the Chilean health system consists of insurers and service providers that can be either public or private. In the case of private insurers, Isapres are entities authorized to receive mandatory health contributions (7% of wages) and are under the supervision of the Superintendency of Health.⁵ The petitioners alleged that the systems of regulation and control of the private health system do not ensure an adequate enjoyment of health care services but allow the rights of patients to be subordinated to the economic interests of the Isapres.⁶
- For its part, the State indicated that "it has a national health system that is amply regulated, in both its public and private spheres." This system "has the Superintendency of Health, which is in charge of protecting and promoting people's rights in the area of health," and "the Health Care Funds and Insurance Authority (*Fondos y Seguros Previsionales de Salud*) [which] ensures that (...) [the] Isapres meet their obligations in terms of satisfying users' rights under the law." According to the State, the health system provides wide coverage and is ranked as one of the most efficient according to international rating agencies.
- 21. Based on what both parties have affirmed, the Commission notes that health insurance includes the additional option of contracting special coverage for catastrophic illnesses, which involves payment of an additional consideration. Activation of CAEC requires that the illness not be qualified by the Isapre as a chronic disease, as the relevant portion of Superintendency of Health Circular No. 7 provides:

10. IN-HOME CARE:

This coverage shall proceed in relation to in-home care, upon request to the Isapre and referral by it to a provider that it designates. For this purpose, all the following conditions must be met: (...) • treatments for chronic diseases and antibiotic treatments are excluded.

- 22. The State said that "the granting or refusal of the agreed coverage by the Isapres may be reviewed and revoked by [the] Superintendency". The dispute settlement model is established in Article 117 of Decree No. 1 of 2005, according to which "the Superintendency, through the Health Care Funds and Insurance Authority, which acts as 'arbitrator-judge,' settles disputes that arise between the [Isapres] and their contributors or beneficiaries, provided that they fall within the sphere of the Superintendency's oversight and control, and without prejudice to the possibility of the insured resorting to the instance referred to in Article 1209 or the regular courts." Likewise, the State also said that a special motion for reversal (*recurso especial de reposición*) could be filed against the decision of the Superintendency, as could an appeal with Superintendent of Health, who decides as an "arbitrator-judge."
- 23. The petitioners said that Isapres "act with the utmost lack of regulation, without a regulatory framework that governs or punishes any arbitrary actions on their part." According to the petitioners, that lack of regulation creates a disproportionate burden for patients, who have to activate litigious dispute settlement mechanisms to demand compliance with their rights.¹¹
- 24. In that connection, the petitioners said that "lawsuits filed against Isapres for unilaterally changing health care plans made up the biggest category of cases on the dockets of the country's Courts of Appeal in 2010, according to the Report of the Presidential Advisory Commission on Health, December 2010." They also said that the insurance market is marked by conflicts of interest that affect access to services, which is the result of the so-called "vertical integration" of the system. According to a report contained in the record "(...) in Chile the Isapres that control the overall market are part of large holdings that encompass both insurers and direct providers of services related to health care, such as clinics and

^{5.} State's brief of January 9, 2018.

^{6.} Initial petition of November 4, 2011.

^{7.} State's brief of January 9, 2018.

^{8.} State's brief of January 9, 2018.

^{9.} Referring to a prior mediation procedure.

^{10.} State's brief of January 9, 2018.

^{11.} Petitioners' brief of March 6, 2017.

^{12.} Initial petition of November 4, 2011.

laboratories. By law, the exclusive purpose of Isapres is to finance health benefits, not provide them or participate in their administration. In short, vertical integration is prohibited, in order to encourage free competition and avoid abuse." ¹³

25. Based on the information available, the IACHR does not find a context of lack of health regulation to the widespread extent mentioned by the petitioner. However, the record suggests that, in the event of a disagreement between an insured and an Isapre, there is a standard system of dispute settlement envisaged in Chile that is activated by the insured against possible impairments of health care services. In addition, the Commission finds that the withdrawal of the CAEC was the result of a decision by the Isapre based on the sole determination that the illness suffered by the insured is a chronic one. The Commission finds that in a specific situation, such as the alleged victim found herself, where the CAEC was lifted, the insured had to invoke some kind of contentious mechanism following the termination of her health coverage.

B. Facts in the case

1. The girl Martina, her diagnoses, and her current situation

- 26. In August 2006, the couple comprising Mr. Vera and Ms. Rojas adopted Martina Vera Rojas when she was three months old. At the age of eight months the Vera girl was diagnosed with Leigh's syndrome. According to the petitioners, Leigh's syndrome is "a progressive, degenerative neurological disorder of genetic origin, characterized by lesions in the thalamus, cerebellum, cerebral cortex and spinal cord. There is no treatment to prevent its progression and patients who suffer from it can only receive palliative care." The petitioners also said that "patients who have this disease usually die before the age of 6 [and] only 27% do not die at an early." That they do not is determined by "the application of kinesiological therapies, frequent diagnoses and prolonged care which includes nutritional support, respiratory therapies, mitochondrial cocktails, all of which must be provided by the same treatment center." 16
- 27. According to the most recent information about Martina, she has already lost her hearing, her vision, her motor system is compromised, she is breathing through a tracheotomy tube, and she is administered food and medicines through a gastrostomy tube.¹⁷ The girl Martina lives with her parents in the city of Arica, in northern Chile. Mr. Vera says that he suffers from nocturnal hypertension, which has caused problems with his sight, while Ms. Rojas says that the family is suffering from constant stress.¹⁸

2. Start of the home hospitalization regimen and its removal

- 28. As was mentioned, Martina's health began to deteriorate when she was eight months old. There is no dispute as to whether the alleged victim suffers from Leigh's syndrome, as the medical reports in the record show.¹⁹ Martina's father contracted health insurance with the Isapre in 2007.²⁰
- 29. After her diagnosis, the petitioners said that when her condition was most critical, she was transferred from Arica to Santiago, where she was hospitalized and fed a special supplement that was

^{13.} Annex XX. Report "La debacle financiera de Isapre MasVida y la indefensión de los usuarios del sistema" [The financial debacle of Isapre MasVida and the defenselessness of system users] by Claudia Urquieta Chavarría. Annex to the petitioners' brief of March 23, 2017.

^{14.} The Commission observes that the possibility also exists of filing an action for protection, which can be triggered by contractual breaches related to the right to property; however, it is not a defining remedy, since it is an "emergency proceeding," as the State indicated to the Commission in its brief of January 9, 2018.

^{15.} Petitioners' brief of March 6, 2017.

^{16.} Petitioners' brief of March 6, 2017.

^{17.} Annex X, Medical report of Dr. Rodrigo Vargas Saavedra of September 30, 2010. Appended to the petitioners' brief of November 4, 2010.

^{18.} Annex X, Psychological report of clinical psychologist Carola Fernández of March 3, 2016. Appended to the petitioners' brief of March 6, 2017.

^{19.} Annex X, Medical report of Dr. Rodrigo Vargas Saavedra of September 30, 2010. Appended to the petitioners' brief of November 4, 2010; Annex X, Medical report of Dr. Oscar Darrigrande of September 25, 2011. Appended to the petitioners' brief of November 4, 2010.

^{20.} Initial petition of November 4, 2011.

mislabeled, further impairing her health.²¹ In September 2007, the family activated the CAEC, so the girl Martina was transferred back to Arica where she was under the in-home care regime (RHD). According to the medical reports in the record, the RHD has been essential to maintain Martina's quality of life. In this regard, a medical report notes that "her good nutritional state and overall condition are striking and difficult to achieve in such patients, which demonstrates that the family and health personnel are administering the therapies effectively and providing good care."²² Another report said that "modern approaches to medicine are clearly oriented toward this type of patient being referred for in-home care. This is a fact and the experience at the public as well as the private level is more than abundant; therefore, sending Martina to a hospital goes against all the approaches recommended by specialists."²³ For the purposes of Martina's care, RHD entails the following equipment and services: "mechanical ventilator, special bed, anti-decubitus mattress, saturation monitors, secretion aspiration motor; Martina also has a tracheotomy and gastrostomy. The local care providers consist of a kinesiologist, two nurses, three paramedical auxiliaries and a doctor."²⁴

- 30. The petitioners said that on October 13, 2010, the Isapre sent a letter to the family informing them that the RHD would terminate on October 28, 2010, because the "GES-CAEC committee, the superior authority of the Isapre (...), has determined, based on the expert opinion of Dr. Rodrigo Var[g]as Saavedra, who reports that the condition of [Martina] is progressive and unrecoverable," that condition of the girl is "chronic" and therefore excluded from RHD in accordance with Article I, point 10, of Circular No. 7. The letter also stated that "in the event that Martina, due to some complication, should require hospitalization at a health care facility, her designated provider is Arica Hospital, her modality of care institutional." This determination that her condition was chronic was a conclusion that the Isapre reached based on an expert medical opinion, as follows: ²⁶
 - 5. (...) in keeping with the expert opinion of the neurosurgeon Dr. Rodrigo Vargas Saavedra, dated September 30, 2010, CAEC under in-home care would only be provided to the child Marina Vera until October 28, 2010, since the services provided derive from a chronic pathology (...) Indeed, the above professional said in his report: "by the clinical history and my review of the tests performed for her diagnosis, her evolution, and her current neurological state, I must conclude that the harm to Martina is severe and unrecoverable, making the prognosis ominous (...)'; therefore, it was possible to conclude that the disease (...) is chronic.
- 31. With regard to the above reasoning, the petitioners included in the record one of their briefs in the arbitration proceeding, in which they reject the interpretation of the Isapre that the expert opinion of Dr. Vargas was aimed at determining the chronicity, or otherwise, of the disease, and assert, rather, that it was a report on the condition of Martina in which the word *chronic* was not used at any time.²⁷ In fact, as detailed below, in his statement in the arbitration proceeding, the aforementioned doctor denies the chronic nature of Leigh's syndrome.²⁸
- 32. The State indicated that "there is no single, special procedure by which insurers can declare that a certain disease is chronic, but given that financing for catastrophic illnesses is determined, in part, by the need for Isapres to control the costs of treatment of such diseases, they are the ones that evaluate each case and decide, based on the medical history in each instance, if it is appropriate that a certain disease be

^{21.} Initial petition of November 4, 2011.

^{22.} Annex X, Medical report of Dr. Rodrigo Vargas Saavedra of September 30, 2010. Appended to the initial petition of November 4, 2011.

^{23.} Annex X, Medical report of Dr. Oscar Darrigrande of July 15, 2011. Appended to the initial petition of November 4, 2011.

^{24.} Annex X, Medical report of Dr. Oscar Darrigrande of October 25, 2011. Appended to the initial petition of November 4, 2011; and Annex X. Certificate of the health care provider Servicios Clínicos S.A. of October 25, 2011. Appended to the initial petition of November 4, 2011.

^{25.} Annex X. Letter from the Isapre to Mr. Vera of October 13, 2015. Appended to the petitioners' brief of March 6, 2017.

^{26.} Annex X. Answer of the Isapre to the arbitral claim, February 29, 2012. Appended to the petitioners' brief of March 6, 2017.

^{27.} Annex X, Petitioners' brief in the arbitral claim, March 5, 2012. Appended to the petitioners' brief of March 6, 2017.

^{28.} Annex X, Witness statement of Dr. Vargas in the arbitral claim, March 7, 2012. Appended to the petitioners' brief of March 6, 2017.

declared chronic." It also said that "such a declaration [that a disease is chronic] must be medically based, so (...) that it can be challenged before the Superintendency."²⁹

- 33. There is no dispute about the start of the litigious stage that triggered two consecutive proceedings: one through a judicial action for protection, the other through a claim to the Superintendency of Health, which are described in detail hereinbelow. It should be noted that the protection action ended with the ruling of the CSJ of May 9, 2011, in which the termination of the RHD was validated.³⁰ Subsequently, the proceeding before the Superintendency concluded on August 27, 2012, with the decision of the Superintendent to resume RHD for Martina.³¹ In summary, the Commission observes that the family of the alleged victim was involved in litigation from October 13, 2010 to August 27, 2012.
- 34. After the CAEC was activated, Martina received three years, or contractual cycles, of RHD. That regime was lifted for the reasons explained above and reinstated as a result of a proceeding before the Superintendency, which meant that from May 9, 2011 to August 27, 2012, the family "was forced to restrict to a minimum the elements that enabled Martina to survive and pay for them by means of solutions that came at a struggle."³²
- 35. In economic terms, the petitioners said that the monthly cost of the basic health plan is USD 203.00 and the annual cost of the CAEC is USD 4,887.00. After the ruling of the CSJ, and the withdrawal of the RHD, Martina's coverage was restricted to USD 92,192.00 per year, that is, USD 7,682.00 per month. According to the information provided, the monthly cost of RHD is USD 12,392.00. The Commission finds the arithmetic difference between the cost of RHD and the coverage after the withdrawal of the CAEC to be USD 4,710.00. The petitioners said that that difference was covered by a special benefit granted by Mr. Vera's employer, on condition that he stayed in that job and that it would be for a limited duration.³³ State did not provide any information in that regard.
- 36. According to the petitioner, the Martina's health worsened during the aforementioned period, as manifested by an "increase in the frequency and duration of respiratory obstructions that she suffered, which [were] increasingly hard to control; a dangerous decrease in her digestive processes; a clear regression in her limited powers of communication and relationship with her surroundings."³⁴ The petitioners also provided a comparative chart of lost and reduced health services at the different stages of the litigation, as a result of which, they said, the family had to assume coverage of the expenses on medicines and medical and paramedical instruments, as well as having to buy the equipment (ventilator, aspirator, pediatric resuscitator, and saturator). State did not provide any information in that regard.

3. The action for protection

37. The information provided by the parties indicates that after being notified of the suspension of the service, Martina's family decided to bring an action for protection on October 26, 2010,³⁵ for the violation of the rights to property, to life, and humane treatment. The Isapre answered the suit, stating that the change in the modality of provision of the CAEC was lawful and that, based on the expert opinion of Dr. Vargas indicating that Martina's condition was progressive and irreversible, RHD was not applicable as the disease was a chronic condition. The Isapre also pointed out that the CAEC had not been completely deactivated, but only that RHD was excluded; and that access to the CAEC is not a "vested right," given that access to it is renewed annually.³⁶

^{29.} State's brief of January 9, 2018.

^{30.} Annex X, Judgment of the CSJ of May 9, 2011. Petitioners' brief of March 6, 2017.

^{31.} Annex X, Appeal Judgment of Judge-Arbitrator Romero Stroy of August 23, 2012. Appended to the petitioners' brief of March 6, 2017.

^{32.} Petitioners' brief of March 6, 2017.

^{33.} Petitioners' brief of March 6, 2017.

^{34.} Petitioners' brief of March 6, 2017.

^{35.} The IACHR places on record that application for the action for protection is not part of the record.

^{36.} Annex X. Answer of the Isapre to the action for protection, November 15, 2010. Appended to the petitioners' brief of March 6, 2017.

- 38. On January 26, 2011, the Court of Appeals of Concepción (hereinafter "the CAC") returned its decision granting the family's claim, taking into consideration that hospital treatment brings risks of intrahospital infections, and therefore, that there was "no rational explanation" for the change in modality of care; that the ISAPRE should not consider it appropriate to exclude RHD in the case of chronic diseases, as indicated in Circular No.7, when someone's life and health depended on it; and that no change in circumstances had been proven such as to justify the replacement of RHD.³⁷
- 39. Isapre appealed against the ruling of the CAC, alleging that RHD legally does not apply to chronic diseases, that CAEC is not a vested right, and that access to RHD is restricted and exceptional.³⁸ On May 9, 2011, the CSJ overturned the decision of the CAC and found in favor of the Isapre. In reaching that decision, the CSJ reasoned that "with regard to so-called in-home care -Circular IF No. 7 (...)- this modality of medical benefit is not appropriate in the case of chronic diseases, the kind of pathology suffered by the patient"; therefore, "the Isapre (...) was able legitimately to deny the application of catastrophic insurance, since it has acted in accordance with the standards that govern the granting of that exceptional benefit."³⁹

4. The proceeding before the Superintendency of Health

- 40. On January 10, 2012, the petitioners filed a claim with the Superintendency seeking the reinstatement of RHD.⁴⁰ The Isapre answered the claim on January 11, 2012, asserting the legality of the decision to lift RHD by reason of the chronic nature of Martina's condition.⁴¹ The petitioners countered, arguing that the Isapre did not take into consideration the special protections under international law, related to the right to life, humane treatment, health, children, and persons with disabilities, that govern such matters, and that according to the Constitutional Court, Isapres have the obligation to respect and protect rights, among other arguments already described.⁴²
- 41. After the debate on evidentiary matters,⁴³ testimony was heard from witnesses on March 3, 2012. The Commission notes that Dr. Vargas,⁴⁴ who reportedly signed the expert opinion from which the chronicity of Martina's condition was deduced, denied that deduction and said that the recommended treatment was RHD, not hospitalization. In a like sense were the statements of Dr. Darrigrande,⁴⁵ the treating physician, and of the kinesiologist Berrios.⁴⁶
- 42. On April 3, 2012, the National Institute of Human Rights of Chile appeared in the proceeding to say that "home medical care should be restored, since its suspension entails a violation of fundamental

^{37.} Annex X, Ruling of the CAC on the application for protection, January 26, 2011, Appended to the initial petition of November 4, 2011.

^{38.} Annex X. Isapre's appeal against the ruling of the CAC of November 15, 2010. Appended to the petitioners' brief of March 6, 2017.

^{39.} Annex X, Appellate ruling of the CSJ of May 9, 2011. Appended to the initial petition of November 4, 2011.

^{40.} Annex X. Claim, Arbitration case 451658-2011, January 10, 2012. Appended to the petitioners' brief of March 6, 2017.

^{41.} Annex X. Answer to claim, Arbitration case 451658-2011, January 11, 2012. Appended to the petitioners' brief of March 6, 2017.

^{42.} Annex X. Comments on answer to claim, Arbitration case 451658-2011, January 16, 2012. Appended to the petitioners' brief of March 6, 2017.

^{43.} Annex X. Comments on the evidence for the claim, Arbitration case 451658-2011, January 29, 2012. Appended to the petitioners' brief of March 6, 2017; Annex X, Incorporation of the evidence for the respondent, Arbitration case 451658-2011, March 5, 2012. Appended to the petitioners' brief of March 6, 2017.

^{44.} Annex X, Statement of Dr. Vargas, March 7, 2012. Appended to the petitioners' brief of March 6, 2017.

^{45.} Annex X, Statement of Dr. Darrigrande, March 7, 2012. Appended to the petitioners' brief of March 6, 2017. Dr. Darrigrande said that "[Martina] could be hospitalized, but it would be inexpedient for her health and for her quality of life and that of her family. (...) "the main drawback is intrahospital infection."

Annex X, Statement of the kinesiologist Berrios, March 7, 2012. Appended to the petitioners' brief of March 6, 2017. The kinesiologist Berrios said: "Martina's health has been fairly stable for a couple of years in the context of her pathology. There were changes when the number of kinesthetic sessions was reduced, specifically in the respiratory area. That was when the Isapre took away [the CAEC], and in order to maintain [the RHD] that decision was made. This situation changed after two weeks, because the two daily sessions resumed in line with Martina's needs." He also said that kinesthetic sessions could be done at a hospital "but the risk of contamination and cross-infections is much higher for Martina."

rights, leaving children in a serious situation of vulnerability (...) in particular, the following rights are affected: 1. Right to health (...) 2. Rights to health of children."⁴⁷

- 43. On April 19, 2012, the Judge-Arbitrator ruled in favor of the reinstatement of RHD for Martina. According to her decision, the hospital regimen was neither feasible nor advisable, despite the chronic nature of her illness, since, given the patient's state of health, it was clear that she would be reinstitutionalized and the hospital designated for her care was not suitable for her long-term admission; therefore, the Isapre would have to move the patient to another region, which would end up generating more costs. She also said that RHD was more favorable for the health of the patient.⁴⁸
- 44. The Isapre filed an application for reconsideration⁴⁹ and the petitioners answered the application.⁵⁰ The judge-arbitrator confirmed her judgment on June 12, 2012,⁵¹ noting that, in her opinion "the restriction established by the CAEC's conditions in order to exclude in-home care from said benefit and only grant it under the health plan's coverage, makes it untenable for the insured to maintain that alternative treatment over time, forcing them to resort to traditional hospitalization, which is more onerous for both parties."⁵² The Isapre filed an appeal and on August 27,⁵³ 2012, the judge-arbitrator, the Superintendent of Health, decided in favor of Martina. The judge-arbitrator considered that he could "base his decision on principles of prudence and fairness to give each party what they deserve and could deviate from the standards in force in order to reach a just solution"; he also found "that there is no debate as to the chronic nature or otherwise of the pathology that affects [Martina], a question that the Tribunal expressly recognizes and, therefore, although in principle, under the rules that govern in-home care within the framework of the CAEC, that nature would exclude said pathology, the very particular circumstances of this case have been taken into consideration" in order to come to the decision that the Isapre Masvida S.A. must continue granting said benefit.⁵⁴

5. The situation after the reinstatement of the in-home care regime

45. The petitioners have sent several communications to the Commission stating that after the reinstatement of the RHD, the new health care provider has not maintained the same quality of care that Martina received previously ⁵⁵ and that the family has to communicate with the Isapre or the Superintendency⁵⁶ in relation to changes or terminations of components of the RHD that they fear could lead to a new attempt to lift said regime. Thus, they informed the IACHR that on April 5, 2016, they advised the Superintendency of their concern regarding an intimidating communication notifying them of an appointment with a physiotherapist,⁵⁷ stating that "the Isapre is entitled periodically to evaluate compliance with the conditions that warrant in-home care."⁵⁸

^{47.} Annex X. Appearance of the Director of the Institute of Human Rights, Lorena Fríes Monleón, April 3, 2012. Appended to the petitioners' brief of March 6, 2017.

^{48.} Annex X, Judgment of Judge-Arbitrator Escobar, Health Care Funds and Insurance Authority, April 19, 2012 . Appended to the petitioners' brief of March 6, 2017.

^{49.} Annex X. Application for reconsideration of the respondent of April 19, 2012. Appended to the petitioners' brief of March 6, 2017.

^{50.} Annex X. Claimant's answer to the application for reconsideration (undated). Appended to the petitioners' brief of March 6, 2017.

^{51.} Annex X, Judgment of Judge-Arbitrator Escobar, Health Care Funds and Insurance Authority, June 12, 2012. Appended to the petitioners' brief of March 6, 2017.

^{52.} Annex X, Confirmation of judgment of Judge-Arbitrator Escobar, Health Care Funds and Insurance Authority, June 12, 2012. Appended to the petitioners' brief of March 6, 2017.

^{53.} Annex X. Appeal of the respondent. Appended to the petitioners' brief of March 6, 2017.

^{54.} Annex X, Appeal Judgment of Judge-Arbitrator Romero Stroy of August 23, 2012. Appended to the petitioners' brief of March 6, 2017.

Annex X. Letter to the Isapre of May 4, 2017. Appended to the petitioners' brief of December 28, 2017.

^{56.} Annex X. Letters to the Superintendency of June 8 and August 3, 2017. Appended to the petitioners' brief of December 28, 2017.

^{57.} Annex X. Letter to the Superintendency of April 5, 2017. Appended to the petitioners' brief of [April] 6, 2017.

^{58.} Annex X. Letter to the Isapre of March 28, 2017. Appended to the petitioners' brief of [April] 6, 2017.

IV. LEGAL ANALYSIS

C. Rights to health and social security (Article 26),⁵⁹ right to life (Article 4.1),⁶⁰ right to humane treatment (Article 5.1),⁶¹ and rights of the child (Article 19),⁶² in conjunction with the obligation to ensure rights and adopt provisions under domestic law contained in Articles 1(1)⁶³ and 2⁶⁴ of the American Convention

1. General considerations on attribution of responsibility

- 46. In the course of their work, the Commission and the Court have sought to define the content of the obligations to respect and ensure rights in accordance with Article 1(1) of the Convention. With respect to the obligation to respect rights, the Court has stated: "According to Article 1(1), any exercise of public power that violates the rights recognized by the Convention is illegal. Whenever a State organ or official, or a public entity violates one of those rights, this constitutes a failure in the duty to respect the rights and freedoms set forth in that Article.⁶⁵ As to the obligation to ensure rights, States must prevent, investigate and punish any violation of the rights recognized by the Convention and, moreover, if possible attempt to restore the right violated and provide compensation as warranted for damages resulting from the violation.⁶⁶
- 47. For its part, the Commission has determined that a violation of the human rights protected by the Convention may engage the international responsibility of a state party, either because the violation is perpetrated by its own agents, or—even if the violations initially are not directly attributable to the State because they were committed by a private individual—when it has not been possible to determine who committed it due to a lack of diligence of the State in reasonably preventing the violation or in treating it in accordance with the provisions of the Convention. The important thing is to determine if the illegal act involved the participation, support or tolerance of state agents or resulted from the failure of the State to meet its obligation to reasonably prevent human rights violations, conduct a meaningful investigation to identify and punish those responsible, and provide adequate reparation the victim or their family members for the harm caused.⁶⁷
- 48. Insofar as this case is concerned, the Court has found that there is a duty to regulate and supervise entities that provide health services.⁶⁸ Although its pronouncements have concentrated on the direct providers of health services, such as clinics,⁶⁹ blood banks,⁷⁰ or psychiatric institutions,⁷¹ the

^{59.} Article 26 of the American Convention provides: "The States Parties undertake to adopt measures, both internally and through international cooperation, especially those of an economic and technical nature, with a view to achieving progressively, by legislation or other appropriate means, the full realization of the rights implicit in the economic, social, educational, scientific, and cultural standards set forth in the Charter of the Organization of American States as amended by the Protocol of Buenos Aires."

^{60.} Article 4(1) of the American Convention provides: "1. Every person has the right to have his life respected. This right shall be protected by law and, in general, from the moment of conception. No one shall be arbitrarily deprived of his life."

^{61.} Article 5(1) of the American Convention provides: "1. Every person has the right to have his physical, mental, and moral integrity respected."

^{62.} The pertinent portions of Article 19 of the American Convention provide: Every minor child has the right to the measures of protection required by his condition as a minor on the part of his family, society, and the state.

^{63.} Article 1(1) of the American Convention provides: "1. The States Parties to this Convention undertake to respect the rights and freedoms recognized herein and to ensure to all persons subject to their jurisdiction the free and full exercise of those rights and freedoms, without any discrimination for reasons of race, color, sex, language, religion, political or other opinion, national or social origin, economic status, birth, or any other social condition.

Article 2 of the Convention provides: "Where the exercise of any of the rights or freedoms referred to in Article 1 is not already ensured by legislative or other provisions, the States Parties undertake to adopt, in accordance with their constitutional processes and the provisions of this Convention, such legislative or other measures as may be necessary to give effect to those rights or freedoms."

^{65.} IACHR, Report No. 11/10, Case 12.488, Merits, Members of the Barrios Family, Venezuela, March 16, 2010, par. 91. Also: I/A Court H.R., Case of Velásquez Rodríguez v. Honduras, Merits, Judgment of July 29, 1988. Series C. No. 4, par. 169.

^{66.} I/A Court H.R., Case of Velásquez Rodríguez v. Honduras, Merits, Judgment of July 29, 1988. Series C. No. 4, par. 166.

^{67.} IACHR, Report No. 65/01, Case 11.073, Merits, Juan Humberto Sánchez, Honduras, March 6, 2001, par. 88.

^{68.} I/A Court H.R., Case of Gonzales Lluy et al. v. Ecuador, Preliminary Objections, Merits, Reparations, and Costs, Judgment of September 1, 2015, Series C. No. 298. par. 175; I/A Court H.R., Case of Ximenes Lopes v. Brazil, Judgment of July 4, 2006. Series C. No. 149. par. 89 and 90.

^{69.} I/A Court H.R., Case of Suárez Peralta v. Ecuador, Preliminary Objections, Merits, Reparations, and Costs, Judgment of May 21, 2013. Series C. No. 261.

Commission considers that those obligations can be extended to private insurance companies that by virtue of their functions can have an impact on the rights to health, life, and humane treatment of people under the jurisdiction of the State. In the present case, under the domestic rules and regulations, Isapres are private-law entities; however, as the proven facts show, they are accorded functions that can be decisive in terms of health care services that a person may or may not receive. Although the Isapres, as insurers, do not provide the health care service directly, they are in charge of managing the contributions that enable the patient to receive said service. Therefore, in this area of the Chilean health care system, it is impossible to envisage final delivery of health care without the involvement of the Isapres. Accordingly, "[t]hough the States may delegate the rendering of such services, through the so-called outsourcing, they continue being responsible for providing such public services [...,] protecting the public interest concerned," overseeing their execution, and ensuring effective protection for human rights as well as access to services without discrimination and in the most effective way possible.⁷²

49. In this case, the Commission finds that the Isapre Masvida SA, a private entity, was authorized by the State to manage the health insurance contributions of workers for their final care in clinical care networks, under the supervision of the Superintendency of Health. Therefore, the Commission will analyze the Isapre's acts in relation to the decision to withdraw in-home care (RHD) in the light of the State's duties in the area of regulation and oversight, in the terms described. That includes the response offered through the internal proceedings by which the family challenged the removal of the RHD.

1. General Considerations in relation to Article 26 and the rights to health and social security

- 50. Article 26 of the Convention establishes the obligation that any measures adopted in the area of the economic, social, and cultural rights covered in that provision tend toward their progressive development. Although both organs of the inter-American system have asserted their competence to pronounce on possible violations of Article 26 of the American Convention within the context of the system of individual cases and petitions,⁷³ that provision has been little developed in the case law of the inter-American system in relation to contentious cases. In its findings in such matters, the Court has emphasized the interdependence and indivisibility that exists between economic, social, and cultural rights and civil and political rights.⁷⁴
- 51. The Commission recognizes that there may be certain complexities to interpreting Article 26 of the Convention and precisely determining its scope and content. Accordingly, the Commission considers it necessary to elaborate on some of its previous statements in that regard, specifically with respect to what it considers an adequate methodology of analysis that takes account of the text of the provision but interprets it in a manner consistent with developments seen in this area at the international level that are highly useful for unraveling its scope and content.
- 52. Thus, the Commission considers that any analysis of a specific case in the light of Article 26 of the American Convention should be done on two levels. First, it is necessary to establish if the right with which the case is concerned derives from "the economic, social, educational, scientific, and cultural standards

^{[...} continuation]

^{70.} I/A Court H.R., Case of Gonzales Lluy et al. v. Ecuador, Preliminary Objections, Merits, Reparations, and Costs, Judgment of September 1, 2015, Series C. No. 298.

^{71.} I/A Court H.R., Case of Ximenes Lopes v. Brazil, Judgment of July 4, 2006. Series C. No. 149.

^{72.} I/A Court H.R., Case of Ximenes Lopes v. Brazil, Judgment of July 4, 2006. Series C. No. 149. par. 96.

^{73.} See, for example, a number of admissibility reports in which the possible violation of Article 26 of the American Convention has been accepted: Report 29/01, Case 12.249, Jorge Odir Miranda Cortez et al., El Salvador, March 7, 2001; and Report 70/04, Petition 667/01, Admissibility, Jesús Manuel Naranjo Cárdenas et al. (Pensioners of the Venezuelan Aviation Company - Viasa), Venezuela, October 13, 2004. See also the core finding on Article 26 Report 38/09, Case 12.670, National Association of Ex-Employees of the Peruvian Social Security Institute et al., Peru, March 27, 2009. Likewise, the Court reaffirmed that competence in the case of Acevedo Buendía et al. ("Discharged and Retired Employees of the Office of the Comptroller") v. Peru, Preliminary Objection, Merits, Reparations and Costs, Judgment of July 1, 2009.

^{74.} See, for example, I/A Court H.R., Case of Lagos del Campo v. Peru, Preliminary Objections, Merits, Reparations, and Costs, Judgment of August 31, 2017, Series C No. 340, par. 141; and Case of Acevedo Buendía et al. ("Discharged and Retired Employees of the Office of the Comptroller") v. Peru, Preliminary Objection, Merits, Reparations and Costs, Judgment of July 1, 2009. par. 101.

set forth in the Charter of the Organization of American States" to which Article 26 refers. In other words, Article 26 of the American Convention recognizes the Charter of the OAS as a direct source of rights and ascribes the Charter's provisions in that regard the character of human rights. Given that the purpose of the Charter of the OAS was not to identify individual rights, but to establish an international organization, auxiliary texts must be relied on to identify the rights that arise from the provisions contained in that instrument.

- 53. Having established that, it must then be determined whether the State breached the obligation in terms of "progressively achieving" the full realization of that right or the general obligations to respect and ensure it. On this second level of analysis, it is necessary to consider the nature and scope of the obligations enforceable upon the State under Articles 1(1), 2, and 26 of the Convention, as well as the content of the right concerned, as is done hereinbelow.
- 54. Insofar as it is the provision that sets out the parameters of the general rules of interpretation of the American Convention, Article 29 of the Convention is important for establishing the criteria by which to derive specific rights from the OAS Charter, as well as to determine their content and the obligations of States in relation thereto. Thus, according to that Article, no provision of the Convention shall be interpreted as restricting or suppressing rights recognized by the domestic laws of the States or by any other treaty to which one of said States is a party, or as excluding the effects that the American Declaration of the Rights and Duties of Man and other international acts of the same nature may have. The provision thus recognizes the *pro persona* principle in the Inter-American system and offers a key tool for effective protection of all human rights recognized both in the constitutions of the states parties, and in the Inter-American and universal human rights instruments that they have ratified.
- 55. Based on a holistic interpretation, which Article 26 requires in light of the provisions contained in article 29, the Commission considers it relevant to refer to the obligations that emerge from Article 26 of the American convention and may be the subject of pronouncements on the part of the organs of the inter-American system in the framework of contentious cases. In that regard, bearing in mind that the State is not a party to the Additional Protocol to the American Convention on Economic, Social and Cultural Rights (Protocol of San Salvador), in this case the International Covenant on Economic, Social and Cultural Rights is relevant, 75 as it contains, at Article 2.1,76 provisions similar to those of Article 26 of the American Convention. The Commission has previously relied on the observations of the Committee on Economic, Social and Cultural Rights on the concept of progressive realization and the scope of obligations arising therefrom. Thus, it underscores that this concept does not render the State's obligations insignificant; on the contrary, it must be interpreted in the light of the overall objective of the treaty with a view to the full realization of the rights involved.
- 56. In light of the foregoing, the Commission finds that Article 26 of the American Convention imposes various obligations on States that go beyond a prohibition on regressiveness, which is a correlate of the obligation of progressive realization and cannot be regarded as the only justiciable obligation in the inter-American system under that provision. Thus, bearing in mind the interpretative framework provided by Article 29 of the American Convention, viewed from the perspective of Articles 1(1) and 2 of that instrument, Article 26 gives rise, at a minimum, to the following immediate and enforceable obligations: (i) general obligations to respect and ensure rights; (ii) application of the principle of nondiscrimination to economic, social, and cultural rights; (iii) obligations to take steps or adopt measures to achieve the realization of the rights contained in that article; and (iv) to offer suitable and effective remedies for their protection. The

^{75.} The Brazilian State acceded to the treaty on January 24, 1992.

^{76.} According to that provision, "Each State Party to the present Covenant undertakes to take steps, individually and through international assistance and co-operation, especially economic and technical, to the maximum of its available resources, with a view to achieving progressively the full realization of the rights recognized in the present Covenant by all appropriate means, including particularly the adoption of legislative measures."

^{77.} IACHR, Report No. 38/09, Case 12.670, Admissibility and Merits, National Association of Ex-Employees of the Peruvian Social Security Institute et al., Peru, March 27, 2009. par. 136.

^{78.} United Nations Committee on Economic, Social and Cultural Rights, General Comment 3: The nature of States parties' obligations (art. 2, para. 1, of the Covenant), adopted at the Fifth Session, 1990, E/1991/23.

appropriate methodologies or sources of analysis for each of those obligations will have to be determined according to the particular circumstances of each case.

- 57. As regards the enforceable and immediate nature of the obligation to take steps or adopt measures, the CESCR has indicated, for example, that the adoption of measures in itself, is not qualified or limited by other considerations; therefore, while the full realization of rights may be achieved progressively, steps towards that goal should be deliberate, concrete and targeted as clearly as possible towards meeting them. The State also has basic obligations to satisfy essential rights that are not subject to progressive realization but are of immediate effect.⁷⁹
- 58. In addition, the IACHR considers that in light of the duty to ensure rights established in Article 1(1) of the American Convention and the interpretation of that provision by the organs of the Inter-American system, states parties have a duty to take reasonable steps to prevent the infringement of the rights contained in Article 26 in the context of business activities. The foregoing includes adopting a legal framework that assures protection for those rights and provides effective access to remedies for victims of such violations. Among the measures for ensuring an adequate legal framework, the State should require business entities under its jurisdiction to exercise human rights due diligence in order to identify, prevent and mitigate the risks of violations of rights in the context of their activities.⁸⁰
- 59. Finally, the organs of the Inter-American system have stressed the duty of states to adopt measures to ensure real equality among people and combat historical or *de facto* discrimination against a variety of social groups. The Commission has indicated that the implementation of positive measures is necessary to ensure that people linked to groups that suffer structural inequalities or have been victims of historical exclusion can exercise their rights.⁸¹ In the same vein, the Court has written that States are obliged "to adopt positive measures to reverse or change discriminatory situations that exist in their societies and that prejudice a specific group of people. This includes the special obligation of protection that the State must exercise with regard to acts and practices of third parties who, with its tolerance or acquiescence, create, maintain or promote discriminatory situations."⁸²
- 60. In applying the above parameters to the instant case, the Commission notes, to begin with, that Article 45 of the Charter of the OAS references the rights to health and social security: Article 34(i) of that instrument also highlights the role of the state in the "[p]rotection of man's potential through the extension and application of modern medical science," emphasizing the importance of the guarantee of health to an individual's integral development. Articles XI of the American Declaration and 12 of the ICESCR also recognize that right. As for the right to social security, that derives from Article 45, paragraphs (b) and (h) of the OAS Charter, which respectively establish the right to protection against unexpected or social risks in relation to work and to development of an efficient social security policy. In turn, more broadly, Article 46 refers to the task of harmonizing standards on social security at the regional level. For its part, the American Declaration enshrines that same right at its Article XVI, as does the ICESCR, at Article 9. As the Commission has noted, it may be necessary to resort to other international instruments to show the derivation of a right based on a public policy measure or objective included in an economic, social, cultural, educational, or scientific provision contained in the Charter of the OAS.⁸³

^{79.} United Nations Committee on Economic, Social and Cultural Rights, General Comment 3: The nature of States parties' obligations (art. 2, para. 1, of the Covenant), 1990. In that connection, see:IACHR, Report on Poverty and Human Rights in the Americas, OEA/Ser.L/V/II.164 Doc. 147 (September 7, 2017), pars. 236 and 237.

^{80.} Committee on Economic, Social and Cultural Rights, General Comment 24, E/C.12/GC/24, August 10, 2017.

^{81.} IACHR, Access to Justice for Women Victims of Violence in the Americas, January 20, 2007, pars. 100 and 101. IACHR, Considerations Regarding the Compatibility of Affirmative Action Measures Designed to Promote the Political Participation of Women with the Principles of Equality and Non-Discrimination, 1999 annual report, April 13, 2000, Chapter VI.

^{82.} I/A Court H.R., Juridical Condition and Rights of the Undocumented Migrants. Advisory Opinion OC-18/03 of September 17, 2003. Series A No. 18, par. 104.

^{83.} Of particular importance are the American Declaration of the Rights and Duties of Man, the International Covenant on Economic, Social and Cultural Rights and the Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights (Protocol of San Salvador), as well as other treaties, including the Convention on the Rights of the Child, the Convention on the Elimination of All Forms of Discrimination against Women, and the Conventions of the International Labour Organization.

- 61. Based on the above, the Commission considers that the rights to health and social security are among the economic and social standards mentioned in Article 26 of the American Convention and, therefore, states parties are under the obligation to seek their progressive development and to respect, ensure, and adopt the necessary measures for the realization of those rights.
- 62. As regards the substance of the right to health, in line with the international *corpus iuris* on the right to health identified by the Court,⁸⁴ in this case the applicable standards can be determined from the development of the scope of the right to the highest attainable standard of health. The ICESCR provides that "[t]he States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health" and establishes that the steps to be taken by the States Parties to achieve the full realization of that right shall include "creation of conditions which would assure to all medical service and medical attention in the event of sickness."
- 63. For its part, the Committee on Economic, Social and Cultural Rights has indicated that all health services, goods and facilities must comply with the requirements of *availability, accessibility, acceptability* and *quality*.⁸⁷ Both the Commission and the Court have taken those concepts into account and have incorporated them in the analysis of various cases.⁸⁸
- 64. In addition, the CESCR has said that, in accordance with the Convention on the Rights of the Child, "children and adolescents have the right to the enjoyment of the highest standard of health and access to facilities for the treatment of illness," and that "[i]n all policies and programmes aimed at guaranteeing the right to health of children and adolescents their best interests shall be a primary consideration." General Comment No. 14 also indicates that the creation of conditions which would assure to all medical service and medical attention in the event of sickness "includes the provision of equal and timely access to basic preventive, curative, rehabilitative health services and ... appropriate treatment of prevalent diseases, illnesses, injuries and disabilities." Finally, the Committee on the Rights of the Child recognizes the existence of a wide array of non-State actors involved in the realization of children's right to health; specifically it says that States must ensure that all non-State actors recognize, respect and fulfill their responsibilities to the child, applying due diligence procedures where necessary.
- 65. The content of the right to social security, includes the consideration that it is closely related to other rights, such as the right to health; and that the withdrawal, reduction or suspension of benefits should be circumscribed, based on grounds that are reasonable and provided in national law.⁹² Where social security schemes are managed by third parties, the State retains the responsibility of regulating and overseeing the social security system and taking reasonable steps to ensure that private sector agents do not violate this right, including framework legislation, independent monitoring, genuine public participation and imposition of penalties for non-compliance.⁹³Likewise, the IACHR recognizes that social health insurance increases utilization of and promotes equity in access to health facilities, goods and services and affords higher levels of financial protection for those who are normally excluded, such as, for example, children with disabilities. Thus, in order for public or private social health insurance programs to have a right-to-health

^{84.} I/A Court H.R., Case of Poblete Vilches et al. v. Chile, Merits, Reparations, and Costs, Judgment of March 8, 2018, Series C. No. 349, par. 114 and ff.

^{85.} ICESCR, Article 12(1).

^{86.} ICESCR, Article 12(2)(d)

^{87.} UN, Committee on Economic, Social and Cultural Rights, General Comment 14, E/C.12/2000/4, 11 August 2000, para. 12.

^{88.} IACHR, Report No. 2/16, Case 12.484, Merits, Cuscul Pivaral et al., Guatemala, April 13, 2016, par. 106; I/A Court H.R., Case of Poblete Vilches et al. v. Chile, Merits, Reparations, and Costs, Judgment of March 8, 2018, Series C. No. 349, par. 120.

^{89.} United Nations, Economic and Social Council, Committee on Economic, Social and Cultural Rights, General Comment 14, E/C.12/2000/4, 11 August 2000, paras. 22 and 24.

^{90.} United Nations, Economic and Social Council, Committee on Economic, Social and Cultural Rights, General Comment 14, E/C.12/2000/4, 11 August 2000, para. 17

^{91.} Committee on the Rights of the Child, General Comment 15, CRC/C/GC/15, 17 April 2013, paras. 75-76.

^{92.} Committee on Economic, Social and Cultural Rights, General Comment 19, E/C.12/GC/19, 4 February 2008. par. 23-28.

^{93.} Committee on Economic, Social and Cultural Rights, General Comment 19, E/C.12/GC/19, 4 February 2008. par. 46.

approach, their design and scope should be informed by the financial capacity and employment status of target populations, but by the specific health needs of those whom they benefit.⁹⁴

2. General standards on the relationship between the right to health and the right to life, the right to humane treatment, and the rights of the child

- 66. Both the IACHR and the Court have pronounced on the relationship that exists between the rights to life and humane treatment and the right to health, 95 while the Inter-American Court has consistently interpreted that the rights to life and humane treatment are directly and closely linked with human health care, 96 and that "lack of adequate medical attention" may contribute to their breach. 97 Furthermore, both bodies have held that States are responsible for regulating at all times the rendering of services and the implementation of the national programs regarding the performance of public quality health care services so that they may deter any threat to the right to life and the physical integrity of the individuals undergoing medical treatment. 98
- 67. The Court has written that "the right to life is a basic human right [that] ... encompasses ... also the right not to be denied the conditions required to ensure a decent existence," which case law has interpreted as also including the provision of, among other things, health care services. 100
- 68. The Commission also finds that the regulation and control of treatment coverage through publicly or privately financed systems must take into account the special situation of children with disabilities. In such circumstances, the Commission has established *prima facie* within the framework of a precautionary measure regarding a girl with disabilities that the state of health and lack of comprehensive support could endanger the rights to life and human treatment. Similarly, the IACHR notes that the development of the rights of children with disabilities recognizes the right to live independently and be included in the community, and by implication, therefore, the right to grow in the family environment, as well as "the existence of adequate and age-appropriate support services for children with disabilities is essential for them to be able to enjoy their human rights on equal terms."

3. Analysis of the case of Martina Vera Rojas in her condition as a girl with disabilities

69. In this case, the Commission will analyze the possible violations of the rights to health, social security, life and humane treatment based on the regulations governing the withdrawal the in-home care regime, the systems for bringing challenges to restore the treatment to Martina, and the responses to those challenges.

^{94.} Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, UN. Doc. A/67/302, 13 August 2012, par. 42-45.

^{95.} IACHR, Report No. 102/13, Case 12.723, Merits, TGGL, Ecuador, November 5, 2013. IACHR, Report: *Access to Maternal Health Services from a Human Rights Perspective*, June 7, 2010, Section II.

^{96.} I/A Court H.R., *Case of Suárez Peralta v. Ecuador*, Preliminary Objections, Merits, Reparations, and Costs, Judgment of May 21, 2013. Series C. No. 261, par. 130; and *Case of Vera Vera et al. v. Ecuador, Preliminary Objection, Merits, Reparations and Costs*. Judgment of May 19, 2011. Series C. No. 226, par. 43.

^{97.} I/A Court H.R., *Case of Suárez Peralta v. Ecuador*, Preliminary Objections, Merits, Reparations, and Costs, Judgment of May 21, 2013. Series C. No. 261, par. 130; *Case of Tibi v. Ecuador*, Preliminary Objections, Merits, Reparations and Costs. Judgment of September 7, 2004. Series C. No. 114, par. 157; and *Case of Vera Vera et al. v. Ecuador*, Preliminary Objections, Merits, Reparations and Costs. Judgment of May 19, 2011. Series C. No. 226, par. 44.

^{98.} I/A Court H.R., *Case of Ximenes Lopes v. Brazil. Preliminary Objection.* Judgment of November 30, 2005. Series C. No. 139, par. 99. See also IACHR, Report No. 102/13, Case 12.723, Merits, TGGL, Ecuador, November 5, 2013.

^{99.} I/A Court H.R., *The "Street Children" Case (Villagrán Morales et al.) v. Guatemala*, Merits, Judgment of November 19, 1999, Series C. No. 63, par. 144 and 191.

^{100.} I/A Court H.R., Case of the Yakye Axa Indigenous Community v. Paraguay, Interpretation of Judgment on Merits, Reparations, and Costs, Judgment of February 6, 2006, Series C. No. 142, par. 161; Case of the Sawhoyamaxa Indigenous Community v. Paraguay, Merits, Reparations, and Costs, Judgment of March 29, 2006, Series C. No. 146, and Case of the Xakmok Kasek Indigenous Community v. Paraguay, Merits, Reparations, and Costs, Judgment of August 24, 2010, Series C No. 214, pars. 194-217.

IACHR, Matter of Irene regarding Argentina, Precautionary Measure No. Resolution 38/2016, July 7, 2016, par. 26.

¹⁰² Committee on the Rights of Persons with Disabilities, General Comment No. 5 (2017) on living independently and being included in the community, CRPD/C/GC/5, 27 October 2017, paras. 19, 74 and 75.

- 70. As established in the proven facts, the Isapre determined that Martina Vera Rojas's disease was a chronic illness and, therefore, based on Circular No. 7, decided that suspension of RHD was appropriate.
- The Commission considers that, based on the right to health, the regulation and oversight of the elements governed by health systems, not only as regards final provision of the service, but also the design of the system's financing through private insurance firms, is a prerogative of the State that must be understood as part of its obligations in terms of creating conditions that assure medical assistance and medical services for all in the event of illness. In the opinion of the IACHR, that aspect demonstrates the indivisibility and interdependence of the right to social security as it relates to health care plans and the right to health, where the former acquires an instrumental or procedural character for satisfying the content of the latter. When such plans are managed by private firms, the State has the obligation to ensure that the design and administration of medical insurance take into account the different elements of the rights to social security and health. Hence, the state's obligation to ensure the effectiveness of human rights produces effects on relations between individuals, who consequently have the obligation to respect them; that is, as regards insurance companies, for instance, the pursuit of profit and economic gain in the medical insurance system must not nullify enjoyment of the rights protected by the American Convention.
- 72. In this case, due to the nature of her illness, Martina received special coverage for catastrophic illnesses, which was precisely designed for complex and costly diseases. This coverage allowed her to receive health care services that, according to the information available, were appropriate for treating her serious health condition, reducing the risks of greater harm, and ensuring a decent life insofar as possible.
- 73. The Commission observes that the current regulation allows for withdrawing RHD on the grounds of chronicity. As has been demonstrated in this case, whether a disease is chronic or not can be difficult to determine and involve a sizable degree of ambiguity and discretion. This is problematic, bearing in mind how decisive such a determination could be for the health of patients who require catastrophic coverage precisely due to the severity of their illness. The State itself acknowledged that "there is no single, special procedure by which insurers can declare that a certain disease is chronic." Furthermore, the regulation offers no apparent safeguards, such as the requirement to assess the situation in which the person would be left in the event of withdrawal of RHD and its implications for their rights to health, life and human treatment.
- 74. Having analyzed Circular No. 7, the Commission notes that the rules on withdrawal of RHD do not establish any type of safeguard with regard the specific impact that such a decision could have on children, who have a special status. In that regard, the Commission recalls that the State has a special duty to protect children because of their progressive physical, cognitive, emotional, psychological, and social development. That duty is heightened when it comes to the enjoyment of the highest attainable standard of health by children, by virtue of their best interests. In this case, the Commission considers that neither the rules and regulations nor the system for challenging decisions made any consideration for Martina's status as a child.
- 75. That much was reflected in this specific instance, where the service was withdrawn by means of simple notice invoking an expert medical opinion—in relation to which the doctor himself later clarified that he had never concluded that Martina's illness was chronic—without any additional verification or determination as to whether her life, health, and integrity might be affected by the immediate withdrawal of RHD, in breach of its obligation to create conditions for ensuring health care. As will be seen below, the CSJ ultimately validated this action on the part of the Isapre without making any assessment of the situation in which Martina would be left as a result of its decision or of the possibilities of providing her a service on whose need and propriety there was a medical consensus. That decision by the CSJ constituted a breach of its duty to oversee the actions of the Isapre and its implications for the rights of a girl with a disability who should have been accorded special protection by the State.
- 76. The IACHR finds that financial accessibility should be one of the characteristics of the right to health, which implies that health facilities, goods, and services should be affordable for all, including socially

¹⁰³ IACHR, Violence, Children, and Organized Crime, OEA/Ser.L/V/II., Doc. 40/15, November 11, 2015, par. 271.

disadvantaged groups. In this regard, the Commission considers that the availability and creation of the CAEC meant that RHD was affordable for Martina at first; however, after the decision of the CSJ, there is no evidence that the State took steps to ensure that the aforementioned regime remained in place or to compensate for the impact of the reduction in her medical coverage, undermining the financial accessibility of the treatment that her illness required, as the petitioners' account of the impact of the withdrawal of RHD on the family shows.

- 77. In line with the foregoing, the Commission finds that the system of challenges available to insureds in the event of a disagreement with their insurance coverage has a standard configuration. In that regard, as the record shows, a claim for undue collection, for example, has the same procedure as a claim against the withdrawal of treatment for catastrophic illness, notwithstanding the impact that the latter may have on the health, life and integrity of a person. In that sense, the Commission considers that the systems of protection for the rights of insureds, due to the special importance of the matters they address, are part of the State's obligations to create conditions that ensure medical assistance in the event of serious illnesses. The Commission finds that the State has not managed to demonstrate that the system of challenges formally available is designed to respond to situations of the sort that arose in this case in keeping with international standards on the rights to health and social security, including special decisions adopted in individual cases involving possible situations of extreme vulnerability like that of Martina.
- 78. In this regard, the Commission notes that the decision of the Isapre to withdraw RHD, as well as the rules governing the granting of that regime, do not stipulate any safeguard in relation to the rights of Martina Vera Rojas as a girl with disabilities. In that regard, the IACHR notes that the CAEC was not totally suspended, but that RHD changed to regular hospitalization as necessary. Thus, as a child with disabilities, the Commission considers that Martina Vera Rojas had the right that her insurance coverage perforce take into account her best interests, her need for support, and her growth in the family environment, not merely the chronicity or otherwise of her condition. In issuing its verdict validating the decision of the Isapre, the CSJ offered no considerations about Martina's particular situation arising from her disability. Likewise, the IACHR cannot help but notice that the reinstatement of RHD, in accordance with the ruling of the Superintendency of Health, was not informed by the best interests of a girl with disabilities and her need to grow in her family environment; rather, it was an economic calculation that is analyzed in depth below.
- 79. In addition to the foregoing, the Commission notes that when the Isapre suspended RHD, the family accessed most of the health services through arrangements and procedures that they undertook themselves. The family purchased some of the equipment and paid from their own funds for medicines and for medical and paramedical instruments; however, they lost the ability to access an air ambulance if Martina needed to be transported to Santiago. Thus, the Commission considers that although Martina was able to access self-managed treatments to maintain the highest attainable standard of health for her, their continued availability was uncertain, wreaked havoc on the family economy, and placed Martina's fragile life and integrity at risk.

4. Conclusion

80. In light of the aforesaid, the State's lack of proper regulation, control, and adequate systems of challenges to control decisions to withdraw RHD from patients with serious and costly diseases, coupled with the lack of protection for the victim in its capacity as guarantor of children's rights, placing her life and health at risk, the Commission concludes that the State is responsible for violation of the rights to health, social security, life, humane treatment, and special protection recognized in Articles 4(1), 5(1), 19, and 26 of the American Convention, taken in conjunction with the obligations established in Articles 1(1) and 2 of the same instrument, to the detriment of Martina Vera Rojas.

D. Right to a fair trial¹⁰⁴ and judicial protection¹⁰⁵ (Articles 8[1] and 25[1]) and rights of the child (Article 19) of the American Convention in connection with Articles 1(1) and 2 thereof

1. General Considerations

- 81. The Commission has underscored that the obligation of the States to act with due diligence includes enabling access to suitable and effective remedies when human rights are violated. ¹⁰⁶ In the case of social rights, because of the complexities associated with their judicial enforceability, the IACHR has stated that the protection of such rights and access to justice are materialized in the recognition of specific fair trial guarantees, such as equality of arms in proceedings, judicial review of administrative decisions, reasoned decisions, and a reasonable time. ¹⁰⁷ Specifically on the subject of equality of arms, the IACHR has held that in judicial proceedings for the protection of social rights "the unequal economic or social status of the litigants frequently has the effect of rendering the possibility of defense unequal at trial." ¹⁰⁸ In that regard, the Inter-American Court has held that "the presence of real disadvantages necessitates countervailing measures that help to reduce or eliminate the obstacles and deficiencies that impair or diminish an effective defense of one's interests." ¹⁰⁹
- 82. In addition, to ensure access to justice, judicial remedies for claiming social rights must be simple, prompt, and effective, as well as offering the possibility to prevent, halt, curb the effects of, and repair the infringement of the infringed human right in situations of stark social inequality. The effectiveness of a remedy must be considered in relation to its possibility of verifying the existence of human rights, of remedying them, of making reparation for the damage done, and of punishing those responsible. The relation to human rights violations in the context of business activities, the CESCR has said: States parties must provide appropriate means of redress to aggrieved individuals or groups and ensure corporate accountability, the remedies be available, effective and expeditious, and that there be access to relevant information for resolving a claim.
- 83. At the same time, considering that in this case the rights of a girl are at stake, the Commission considers it necessary to incorporate the international *corpus iuris* for the protection of children into its analysis of this case. ¹¹⁴ The Commission and the Inter-American Court have held that "children are beneficiaries of the rights enshrined in the American Convention, as well as enjoying special protective

Article 8 of the American Convention provides: 1. Every person has the right to a hearing, with due guarantees and within a reasonable time, by a competent, independent, and impartial tribunal, previously established by law, in the substantiation of any accusation of a criminal nature made against him or for the determination of his rights and obligations of a civil, labor, fiscal, or any other nature.

Article 25 of the American Convention states: 1. Everyone has the right to simple and prompt recourse, or any other effective recourse, to a competent court or tribunal for protection against acts that violate his fundamental rights recognized by the constitution or laws of the state concerned or by this Convention, even though such violation may have been committed by persons acting in the course of their official duties.

¹⁰⁶ IACHR, Access to Justice for Women Victims of Violence in the Americas, OEA/Ser. L/V/II. doc.68, January 20, 2007.

¹⁰⁷ IACHR, Access to Justice as a Guarantee of Economic, Social, and Cultural Rights. A Review of the Standards Adopted by the Inter-American System of Human Rights, OEA/Ser.L/V/II.129, Doc. 4, September 7, 2007, par. 177 and ff.

IACHR, Access to Justice as a Guarantee of Economic, Social, and Cultural Rights. A Review of the Standards Adopted by the Inter-American System of Human Rights, OEA/Ser.L/V/II.129, Doc. 4, September 7, 2007, par. 188.

¹⁰⁹ IACHR, Access to Justice as a Guarantee of Economic, Social, and Cultural Rights. A Review of the Standards Adopted by the Inter-American System of Human Rights, OEA/Ser.L/V/II.129, Doc. 4, September 7, 2007, par. 185.

IACHR, Access to Justice as a Guarantee of Economic, Social, and Cultural Rights. A Review of the Standards Adopted by the Inter-American System of Human Rights, OEA/Ser.L/V/II.129, Doc. 4, September 7, 2007, par. 259.

¹¹¹ IACHR, Access to Justice as a Guarantee of Economic, Social, and Cultural Rights. A Review of the Standards Adopted by the Inter-American System of Human Rights, OEA/Ser.L/V/II.129, Doc. 4, September 7, 2007, par. 248.

¹¹² Committee on Economic, Social and Cultural Rights, General Comment No. 24, E/C.12/GC/24, 10 August 2017, para. 39. See also, United Nations Guiding Principles on Business and Human Rights, Access to Remedy (Principle 25) (2011), available online: http://www.ohchr.org/Documents/Publications/GuidingPrinciplesBusinessHR_EN.pdf

¹¹³ Committee on Economic, Social and Cultural Rights, General Comment No. 24, E/C.12/GC/24, 10 August 2017, paras. 41 and 45.

IACHR, Report No. 102/13, Case 12.723, Merits, TGGL, Ecuador, par. 149. Cf. I/A Court H.R., *Case of Fornerón and daughter v. Argentina*, Merits, Reparations, and Costs, Judgment of April 27, 2012, Series C. No. 242, par. 44; I/A Court H.R., *Case of Furlan and Family v. Argentina*, Preliminary Objections, Merits, Reparations, and Costs, Judgment of August 31, 2012. Series C. No. 246, par. 125.

measures set out in Article 19, which must be interpreted according to the particular circumstances of each case at hand."115 Moreover, "the State must pay special attention to the needs and rights of the child, considering [their] particular condition of vulnerability."116 In that connection, Article 3.1 of the Convention on the Rights of the Child is relevant; 117 it provides: "In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration." Furthermore, in Advisory Opinion OC-17/2002, the Court considered that "while procedural rights and their corollary guarantees apply to all persons, in the case of children exercise of those rights requires, due to the special conditions of minors, that certain specific measures be adopted for them to effectively enjoy those rights and guarantees." 118

2. Analysis of the case

- 84. The Commission observes that in this case two proceedings were activated: the judicial action for protection and the proceeding before the Superintendency of Health. The IACHR will analyze the effectiveness of the remedies, the reasoning for the rulings, and how they relate to the best interests of the child.
- 85. The Commission notes that the protection action was filed for alleged violations of the rights to property, life and humane treatment. Therefore, the moment the mother and father had recourse to the law courts there were obstacles to directly arguing the violations of the right to health analyzed in this report, given that under Article 20 of the Constitution of Chile, actions for protection in matters related to the right to health—governed by Article 19, paragraph 9—are admissible with respect to the right to choose the health system; the protection action does not apply to the right to social security governed by paragraph 18 of the same article. In this regard, the Commission does not consider that the protection action was suitable to hear allegations related to the right to health, which in this case went beyond the revision of contractual conditions. The content of the decision of the CSJ, which makes no reference to the implications of the Isapre's decision for Martina's rights to health and social security, reflects of that situation.
- 86. However, as the State has indicated, a specially designed remedy exists for matters related to the coverage of the Isapres before the Superintendency, which includes an evidentiary stage and a hearing for the better cognizance of the judge-arbitrator. The Commission finds that, the judge-arbitrator does indeed have the power not only to decide under the standards in force, resolve not only in application of the current regulations, but also to pass sentence with a measure of discretion and on the basis of sound judgment. Therefore, the IACHR considers that although the process is not designed to declare a violation of the right to health, since it is confined to contractual analysis and the right to property, from the actions of the petitioners in the proceedings, the Commission finds that information was put forward and evidence was adduced in relation to the right to health. In this regard, the Commission observes that the favorable outcome of this remedy for Martina was due to the fortune of having had a judge-arbitrator who, in exercising his discretion, took the right to health into account, but it was not the result of a system adequately designed for such purposes.
- 87. As for the reasoning for the judgments, the Commission was struck by how the CSJ narrow-mindedly determined automatically that, inasmuch as the Isapre concluded that the disease was chronic and that chronicity was stipulated in the Circular No. 7 as a cause for the withdrawing RHD, then it was right to confirm that decision. In this regard, the Commission considers that while the reasoning is ostensibly objective—given the legality of the decision bearing in mind Circular No. 7, under international standards on the rights to health and social security, which must be assessed with particular care where children and

IACHR, Report No. 102/13, Case 12.723, Merits, TGGL, Ecuador, par. 150. Cf. I/A Court H.R., *Case of Fornerón and daughter v. Argentina*, Merits, Reparations, and Costs, Judgment of April 27, 2012, Series C No. 242, par. 44; I/A Court H.R., *Case of Gelman v. Uruguay*, Merits and Reparations, Judgment of February 24, 2011, Series C No. 221, par. 121.

¹¹⁶ I/A Court H.R., *Case of Rosendo Cantú et al. v. Mexico*, Preliminary Objection, Merits, Reparations, and Costs, Judgment of August 31, 2010, Series C. No. 216, par. 201.

¹¹⁷ Convention on the Rights of the Child, Resolution 44/25, 20 November 1989.

¹¹⁸ I/A Court H.R., Juridical Condition and Human Rights of the Child, Advisory Opinion OC-17/02 of August 28, 2002. Series A No. 17. par. 98.

persons with disabilities are concerned, the State was supposed to analyze the specific case taking into account whether restricting RHD based on the chronicity of a disease was compatible with the girl's right to the health and the best interests. Likewise, in finding the removal of RHD to be lawful, the CSJ should also have evaluated the unprotected state in which Martina would be left and the role of the State in compensating for possible medical services that would no longer be covered by private insurance but were necessary for her particular health condition. All those fundamental aspects are absent from the decision of the CSJ.

- At the same time, although the decision of the Superintendency reinstated RHD for Martina, that decision was based solely on the cost-benefit of its withdrawal for the Isapre. Thus, the reasoning of the judge-arbitrator was founded on the fact that if RHD was removed, Martina would eventually be admitted to the hospital assigned by the insurer. In that connection, since the hospital was not equipped for a long-term stay, Martina would have had to be transferred to another health facility farther away, increasing the costs for the Isapre; therefore, in this specific case the judge-arbitrator concluded that although Martina's illness was chronic, the provisions of Circular No. 7 could be set aside and RHD reinstated. As in the previous case, the Commission considers that there is also no reasoning addressing the tension between the chronicity cause contained in Circular No. 7 and the best interests of the Martina in relation to her rights to health and social security. Based on the foregoing, the Commission finds that if a new hospital space were created with the capacity to admit Martina for a longer period, she would lose the treatment in dispute, since its grant was not based on the need for it to affordable so as to avoid infringements of her rights to health, social security, humane treatment and to facilitate an independent life for her by enabling her to grow in her family environment as a child with a disability.
- 89. Likewise, in the case of both decisions, the IACHR does not find any clear reasoning in relation to the determination of Martina's illness as chronic. Moreover, the IACHR considers that there are serious doubts and contradictions in relation to the specialists and the Isapre's interpretation of them which were not clarified in the rulings, especially the last one in which it was determined that Martina's illness was chronic. However, even if chronic, the Commission considers that this criterion for suspending RHD should have been analyzed in the light of the American Convention, in order to determine whether in this specific case its direct application violated Martina's human rights, especially considering the existence of important medical indications—accredited in this report—that the best thing for her fragile life and health was RHD and that her surroundings by her family environment.
- 90. Based on the foregoing, the Commission concludes that the State of Chile is responsible for violation of the rights to a fair trial and judicial protection and the rights of the child with disability recognized in Articles 8(1), 25(1), and 19 of the American Convention, taken in conjunction with the obligations to respect and ensure rights established in Articles 1(1) and 2 of the same instrument, to the detriment of Martina Vera Rojas.

E. The right to humane treatment (Article 5[1]) of Mr. Vera and Ms. Rojas, taken in conjunction with Article 1(1) of the American Convention

91. The Commission and the Inter-American Court have indicated that the next-of-kin of victims of certain human rights violations may, in turn, be considered victims. ¹¹⁹ In that regard, the Court has ruled that their right to mental and moral integrity [may be] violated based on the particular circumstances of the violations perpetrated against their loved ones and owing to the subsequent acts or omissions of the State authorities in relation to the facts. ¹²⁰

¹¹⁹ IACHR, Report No. 11/10. Case 12.488, Merits, Barrios Family, Venezuela, March 16, 2010, par. 91. IACHR, Report on Terrorism and Human Rights. par. 227; I/A Court H.R., Case of Poblete Vilches et al. v. Chile, Merits, Reparations, and Costs, Judgment of March 8, 2018, Series C. No. 349, par. 201; I/A Court H.R., Case of Cantoral Huamaní and García Santa Cruz v. Peru, Preliminary Objection, Merits, Reparations and Costs. Judgment of July 10, 2007. Series C. No. 167, par. 112; and Case of Bueno-Alves v. Argentina, Merits, Reparations, and Costs, Judgment of May 11, 2007. Series C No. 164, par. 102.

¹²⁰ I/A Court H.R., Case of Cantoral Huamaní and García Santa Cruz v. Peru, Preliminary Objection, Merits, Reparations and Costs. Judgment of July 10, 2007. Series C. No. 167, par. 112; and Case of Vargas-Areco v. Paraguay, Judgment of September 26, 2006. Series C. No. 155, par. 96.

- 92. Specifically with regard to the analysis of the State's international responsibility for violation of the right to humane treatment of family members arising from infringements of the victims' right to health, the Court has established that this type of violation must be proven. ¹²¹ In that regard, the petitioners documented that the mother and father suffer with post-traumatic stress arising from the suffering caused by the uncertainty of access to the treatment that keeps their daughter alive. In this way, the expert psychological opinion said that "after feeling that their daughter was not protected by the State, the sensation took root in both of being unable to ensure the necessary care for their daughter" and that the psychological consequences were feelings of uncertainty, helplessness, distrust, hypervigilance and hyper-alertness, humiliation, anger, and avoidance. The opinion concluded that it was a case of chronic post-traumatic stress disorder. ¹²² In addition, as already proven in this report, the highly litigious relationship between the Isapre and Martina's parents due to the unilateral changes in access to the proper treatment, in itself caused Martina's parents suffering due to the lack of adequate regulation of RHD withdrawal. Based on the foregoing, the Commission finds that there is a causal link between the suffering experienced by Mr. Vera and Ms. Rojas and the facts analyzed in this case.
- 93. In addition to the above, the Inter-American Court has indicated that the right to humane treatment of the next-of-kin can be affected by the close family relationship and the efforts made to obtain justice. ¹²³ In this case, as already mentioned, given the quest to ensure treatment for Martina through the above-accredited litigation and the obviously close family bond between the parents and their daughter in her seriously vulnerable condition, one can infer that the alleged suffering was only logical.
- 94. Consequently, the Commission concludes that the State violated the right of Mr. Vera and Ms. Rojas to have their mental and moral integrity respect, as recognized in Article 5.1 of the American Convention, taken in conjunction with the obligations set out in Article 1(1) thereof.

V. CONCLUSIONS AND RECOMMENDATIONS

95. Based on the findings of fact and law, the Inter-American Commission concluded that the State is responsible for the violation of Articles 4(1) (right to life), 5(1) (right to humane treatment), 19 (rights of the child with disability), 26 (right to health), and 8(1) and 25(1) (rights to a fair trial and judicial protection) of the American Convention on Human Rights, in relation to the obligations established in Articles 1(1) and 2 of the same instrument.

THE INTER-AMERICAN COMMISSION ON HUMAN RIGHTS RECOMMENDS THAT THE STATE OF CHILE:

- 1. Provide full reparation for the human rights violations found in the instant report, including both material and nonpecuniary dimensions. The state should adopt measures of economic compensation and satisfaction.
- 2. Arrange for Ramiro Vera Luza and Carolina Rojas Farías to receive the necessary physical and mental health care for their rehabilitation, if they so wish and in a manner that meets with their agreement.
- 3. Ensure that Martina Vera Rojas' in-home care regime remains in effect for as long as she needs it. As part of this recommendation, any future determination made on said regime must comply with the standards described in this report and have as its primary consideration the best interests of the victim as a child with a disability.

¹²¹ I/A Court H.R., Case of Poblete Vilches et al. v. Chile, Merits, Reparations, and Costs, Judgment of March 8, 2018, Series C. No. 349, par. 203.

¹²² Annex X, Psychological report of clinical psychologist Carola Fernández of March 3, 2016. Appended to the petitioners' brief of March 6, 2017.

¹²³ I/A Court H.R., Case of Poblete Vilches et al. v. Chile, Merits, Reparations, and Costs, Judgment of March 8, 2018, Series C. No. 349, par. 208.

4. Provide non-repetition mechanisms that, *inter alia*: (i) ensure that the process before the Superintendency of Health on disputes between Isapres and insureds over the withdrawal of medical benefits for serious diseases conforms to the standards established in this report; and (ii) ensure that there are adequate and expeditious judicial remedies to challenge possible decisions by the Isapres that may affect the rights to health and social security of a person and endanger their life and well-being.