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REPORT No. 75/20
PETITION 1011-11
REPORT ON ADMISSIBILITY

GABRIEL ALEJANDRO VASCO TOAPANTA ET AL.
ECUADOR

Approved electronically by the Commission on April 24, 2020.

Cite as: IACHR, Report No. 75/20, Petition 1011-11. Admissibility. Gabriel Alejandro Vasco Toapanta et al. Ecuador. April 24, 2020.

I. INFORMATION ABOUT THE PETITION

Petitioner:	Santiago Vasco Morales, Christian Oswaldo Asanza Reyes, Juan Pablo Albán Alencastro, Beatriz Meythaler, and Gabriela Flores
Alleged victim:	Gabriel Alejandro Vasco Toapanta et al ¹
Respondent State:	Ecuador
Rights invoked:	Articles 4 (right to life), 5 (right to humane treatment/personal integrity), 8 (right to a fair trial/judicial guarantees), 19 (rights of the child), and 25 (right to judicial protection) of the American Convention on Human Rights ² ; VI (right to a family and to protection thereof), XI (right to the preservation of health and to well-being), and XXIV (right of petition) of the American Declaration of the Rights and Duties of Man ³ ; and other international treaties. ⁴

II. PROCEEDINGS BEFORE THE IACHR⁵

Filing of the petition:	July 27, 2011
Additional information received at the stage of initial review:	August 15 and 17, 2011
Notification of the petition to the State:	March 11, 2014
State's first response:	November 4, 2014
Additional observations from the petitioner:	December 11 and 14, 2014; March 11 and December 28, 2015; June 21, 2016; May 22, June 29, September 20, 2017; and November 6, 2018.
Additional observations from the State:	May 14, 2015; January 27 and September 11, 2017; April 29 and July 20, 2019.

III. COMPETENCE

Competence <i>Ratione personae</i>:	Yes
Competence <i>Ratione loci</i>:	Yes
Competence <i>Ratione temporis</i>:	Yes
Competence <i>Ratione materiae</i>:	Yes

IV. DUPLICATION OF PROCEDURES AND INTERNATIONAL *RES JUDICATA*, COLORABLE CLAIM, EXHAUSTION OF DOMESTIC REMEDIES AND TIMELINESS OF THE PETITION

Duplication of procedures and International <i>res judicata</i>:	No
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¹ The petition refers to "approximately" 30 children said to be suffering from Laron Syndrome, eight of whom it identifies. It also describes facts that could amount to violations of the human rights of their parents, eight of whom are also identified in the petition 8. The alleged victims identified in the petition are listed in the document attached to this report.

² Hereinafter the "American Convention."

³ Hereinafter the "American Declaration."

⁴ Articles I, III, and IV of the Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities and Article 12 of the International Covenant on Economic, Social and Cultural Rights.

⁵ The observations submitted by each party were duly transmitted to the opposing party.

Rights declared admissible	Articles 4 (right to life), 5 (right to humane treatment/personal integrity), 8 (right to a fair trial/judicial guarantees), 19 (rights of the child), 24 (right to equal protection), 25 (right to judicial protection), and 26 (economic, social, and cultural rights) of the American Convention, in conjunction with Articles 1.1 (obligation to respect rights) and 2 (domestic legal effects/duty to adopt domestic legal provisions); and Article XI (right to the preservation of health and well-being) of the American Declaration.
Exhaustion of domestic remedies or applicability of an exception to the rule:	Yes, as referred to in Section VI
Timeliness of the petition:	Yes, as referred to in Section VI

V. FACTS ALLEGED

1. The petitioning party reports alleged violations of the human rights of Gabriel Alejandro Vasco Toapanta and "approximately" 30 children with Laron Syndrome (hereinafter "the alleged victims"). It points out that this illness generally stunts the growth of those suffering from it, creating disability, but that a drug exists that can prevent those consequences if it is administered to the patient before he or she reaches puberty. It alleges that this drug is not available in Ecuador as it lacks approval from the sanitary registry and that the State has not complied with its obligation to adopt measures to enable sick children to access the treatment, despite two domestic court orders to comply with those obligations. It maintains that irreparable harm has been done to some of the alleged victims, because they reached puberty without having received the treatment.

2. The petitioning party points out that Laron Syndrome is a congenital disease caused by an anomaly in the gene encoding the growth hormone receptor, which causes markedly short stature (between -4 and -11.5 below the average") and facial dysmorphism. It argues that the consequences include risks in carrying out day-to-day activities, delay in learning to walk, limited joint movements, hypoglycemia, high cholesterol, obesity, hip dysplasia, and delayed motor development. It maintains that, although, globally, this is an extremely rare disease, Ecuador accounts for one third of all those affected by it in the world. It alleges that the State labels Laron Syndrome a "catastrophic disease," in accordance with the Organic Health Act and issues disability certificates to those suffering from it.

3. It maintains that there is no cure for this syndrome and that the only treatment developed for it is a medicine containing Mecasermin, which, when administered prior to puberty, may allow those with the syndrome to attain a stature that does not trigger disability (it states that average growth of people with the syndrome is 2-3cm per year, but the medicine can increase that to 9.3 cm per year). The petitioning party says that the medicine is marketed under the brand name Increlex, which has been approved by the Food and Drug Administration in the United States and by the European Medicines Agency, and that the only laboratory producing it is located in France. It points out that the medicine is not registered for distribution in Ecuador and is an "orphan drug" with few commercial prospects on the market since it is used only for Laron Syndrome, which is an extremely rare disease; thus, the private sector in Ecuador has had no incentive to push for its registration by the health authorities. It adds that the drug is very expensive (the cost for a patient weighing 18 kg would be approximately US\$2,400 per month), which means that no individual can defray the cost of registering and importing it.

4. It states that, since 2007, requests have been filed and attempts made to approach various state institutions in the hope that they would help the alleged victims gain access to the treatment, but that the State has not provided any assistance. On September 20, 2010, a group of parents⁶ filed a suit for protection under the Constitution against the Health Minister, asking that persons with Laron Syndrome at all stages of the disease be granted specialized, cost-free care and that permission be granted to import the drug INCRELEX into Ecuador. On December 2, 2010, the Second Criminal Guarantees Court (*Tribunal Segundo de Garantías*

⁶ They are the eight persons listed in the document attached to this report.

Penales) in Pichincha granted the suit for protection and ordered that a bipartite commission be formed, made up of those bringing the lawsuit, a doctor, and expert researcher into Laron Syndrome, and representatives of the Ministry of Public Health; that the plaintiffs submit to the Health Ministry within 30 days a technical guidelines protocol on the Laron Syndrome; and that the Ministry of Health, once it has received the protocol, make arrangements for the effective and expeditious delivery, within a reasonable period of time, of medical support for the treatment of the Laron Syndrome to all Ecuadorians suffering from it, via the National Secretariat for Higher Education, Science, and Technology (ENESCYT). The petitioning party goes on to say that the plaintiffs delivered the protocol on December 16, 2010, but the Health Ministry has not complied with the court order. It points out that, although the Bipartite Commission was installed, it did not meet on a regular basis, and that, although the Ministry of Health presented a project to the Secretariat, the latter rejected it because it did not meet its requirements. The Ministry then never did submit a project meeting those requirements.

5. The petitioning party points out that the failure to comply with the court order was reported to the Court that had issued it, which led the Court to issue instructions to the Health Ministry on December 23, 2010 and on March 15 and May 20, 2011 to comply with its ruling. It adds that the noncompliance was also reported on March 4, 2011 to the Office of the Ombudsperson (*Defensoría del Pueblo*) and again, in a letter addressed to the President of Ecuador, on June 27, 2011. It states that, on February 17, 2014, a suit was filed for noncompliance with the judgment three years after it had been handed down. The petitioning party considers that the time that elapsed between issuance of the judgment and the filing of the suit for noncompliance with it should not be invoked by the State to justify its delay in complying, because the norm must be that court orders are to be executed, so that the suit brought for noncompliance must be construed as an extraordinary remedy. On February 28, 2014, the Second Criminal Guarantees Court in Pichincha declared failure to comply with its order and referred the case to the Constitutional Court. The petitioning party complains that the suit for noncompliance, which by its very nature calls for a quick decision, was not resolved within a reasonable period of time; judgment was handed down on December 12, 2016, whereas the whole set of domestic provisions on the subject called for the Constitutional Court to resolve the matter in approximately 50 days.

6. It points out that the Constitutional Court ruling ordered a series of measures on behalf of the alleged victims: such as the instruction to the Health Ministry to initiate within 60 days the procedures required to register INCRELEX as an approved medicine and the instruction "by virtue of the *inter comunis* effect of the present judgment, to the representative of the Ministry of Public Health to proceed, as soon as procedures began to register INCRELEX as an approved medicine, to supply it to the children who needed it, provided that their legal representatives had granted their informed consent and the Public Health Ministry had certified that they were suffering from Laron Syndrome"; as well as the instruction to the Ministry of Finance to allocate the funds needed to purchase INCRELEX on an ongoing basis. The petitioning party alleges that this second court ruling in favor of the alleged victims was not complied with, either. Accordingly, it complains that the Constitutional Court did not take steps to demand compliance with its ruling, despite the fact that by law it was entitled to do so.

7. It considers that noncompliance by State authorities with two court orders on behalf of the alleged victims is evidence of a lack of effective judicial protection. It underscores that the French firm producing INCRELEX has expressed its willingness to make the medicine available to Ecuador, and even to provide it free of charge in certain cases. In spite of that, the State has done everything to prevent registration of the medicine and has rejected any agreement with the laboratory making it. It has even prevented parents from bringing in the medicine from abroad on their own responsibility. The petitioning party alleges that the State has prevented the persons affected by the Syndrome from having access to conditions that would enable them to live in dignity, thereby violating Article 4 of the American Convention. It also argues that the State has failed to comply with its obligations toward persons with disabilities and has caused irreparable harm to some of the alleged victims who allegedly will no longer be able to benefit from the treatment as they have completed their bone development.

8. For its part, the State stated in its initial briefs that the petition should not be admitted due to failure to exhaust domestic remedies, because a ruling in a noncompliance suit was still pending and that said suit offered an ideal remedy for the complaints lodged by the petitioners before an international body. It stressed that the noncompliance suit had been filed more than three years after issuance of the judgment that the petitioners claimed had not been complied with, and stated that it considered that such a delay showed a lack of motivation on the petitioners' part, which exempted the State from any responsibility. The State likewise alleged that the petitioning party was trying to get the Inter-American Commission to pronounce on the right to health, an area in which it lacks competence *ratione materiae*. It further argued that it had not been demonstrated that the persons suffering from Laron Syndrome had seen their quality of life diminish and it emphasized that INCRELEX was an unregistered experimental medicine, with various adverse effects on those who take it.

9. In its writ of April 29, 2019, the State reported that, in compliance with the judgment of the Constitutional Court of December 12, 2016, INCRELEX was now registered by the health authorities and that on December 20, 2018 a resolution had been passed capping the price that could be charged for it. Said resolution had been published on February 8, 2019. The State also indicated that the Ministry of Health had provided comprehensive care for persons with Laron Syndrome and continued to identify patients. In its final writ, dated June 20, 2019, the State pointed out that the National Under-Secretary for the Provision of Health Services had requested the National Secretary for Health Governance to remit the Protocol for Treating Patients with Laron Syndrome, along with the legal consent form to be signed by the legal representatives of the target population, with a view to drawing up a complete list of patients for whom administration of the medicine was recommended. The aforementioned Under-Secretary also requested that the requisite steps be taken to identify the patients for whom the medicine could be recommended in accordance with international parameters and ordered several medical tests of patients with Laron Syndrome. The State also indicated that the Ministry of Public Health had drawn up preliminary documents, such as a care flow for patients with Laron Syndrome and that said Ministry was continuing to report to the Constitutional Court on progress made with complying its above-mentioned judgment.

VI. ANALYSIS OF EXHAUSTION OF DOMESTIC REMEDIES AND TIMELINESS OF THE PETITION

10. The Commission notes that the petitioning party considers that domestic remedies were exhausted with the ruling of December 2, 2010 which granted the protection suit filed on behalf of the children with Laron Syndrome. It likewise notes that at the time the State argued that domestic remedies had not been exhausted while that decision in a noncompliance suit was still pending.

11. The present petition alleges noncompliance with a court judgment more than nine years after it was handed down. The Commission observes that on February 28, 2014, failure to comply was formally acknowledged, so that on December 12, 2016 the Constitutional Court handed down a judgment ordering measures of compliance. However, from the information in the file it transpires that the process of monitoring compliance with those measures by the Constitutional Court reportedly remains open more than three years after the judgment was handed down. That being so, the Commission concludes, as it has done in other cases alleging unwarranted delay in complying with a court judgment, that the exception to exhaustion of domestic remedies contemplated in Article 46.2.c of the American Convention is applicable.⁷ Given that the petition was lodged while the alleged wrongs giving rise to it were in effect and after assessing the arguments regarding the consequences that could ensue for the alleged victims from their not receiving the INCRELEX medicine in time, the Commission concludes that the petition was lodged within a reasonable time under the terms of Article 32.2 of its Rules of Procedures.

⁷ IACHR, Report N° 18/17, Petition 267-07. Admissibility. Ana Luisa Ontiveros López. Mexico. January 27, 2017, paras. 6 and 7.

12. In addition, the Commission deems that, although the lawsuits were filed only by eight parents of children allegedly suffering from Laron Syndrome, the court orders reportedly not complied with were to benefit children affected by the syndrome in general. For that reason, the Commission considers that domestic remedies were exhausted in respect of all the alleged victims.

VII. ANALYSIS OF COLORABLE CLAIM

13. The Commission observes that although the petitioning party referred to "approximately" 30 children reportedly with Laron Syndrome, only 8 were identified. On this, the Commission once again points out that the American Convention does not contain restrictions on competence in terms of "full and total" identification of persons affected by the violation. Rather, it permits the review of human rights violations that -- because of their particular characteristics, may affect a particular person or group of persons who are not necessarily fully identified.⁸ In the instant case, the Commission does not consider that the State's right to defense was impaired by the absence of full identification of all alleged victims nor has the State argued that it was. For those reasons, and given the nature of this case, the Commission considers, as it has in other cases, that full identification of all victims must be determined on the basis of the evidence provided by the parties at the merits stage.⁹

14. The Commission observes that the present petition alleges as follows: that the State unjustifiably failed to adopt measures that it could have adopted and that were necessary measures to guarantee the rights of children with Laron Syndrome; that the judicial authorities violated due process of law and failed to act within a reasonable period of time; that a court order was not fully implemented eight years after it was issued and more than two years after a decision was reached on a lawsuit demanding compliance; and that the delay in executing judgments has caused irreparable harm to some of the alleged victims.

15. In light of those considerations and after examining the matters of fact and law raised by the parties, the Commission deems that the allegations of the petitioning party are not manifestly groundless and require an assessment on their merits because the facts alleged, if corroborated as true, could characterize violations of Articles 4 (right to life), 5 (right to humane treatment/personal integrity), 8 (right to a fair trial/judicial guarantees), 19 (rights of the child), 24 (right to equal protection), 25 (right to judicial protection), and 26 (economic, social, and cultural rights) of the American Convention, in conjunction with Articles 1.1 (obligation to respect rights) and 2 (domestic legal effects).

16. In relation to the alleged violations of Article XXIV (petition) of the American Declaration, this Commission has previously established that once the Convention has entered into force in a State, it and not the Declaration becomes the principal source of law to be applied by the Commission, as long as the petition alleges violation of substantially identical rights set forth in both instruments and a continuing situation is not involved. In this case, the alleged violations of these articles match the framework of protection provided by Articles 8 and 25 of the American Convention. Therefore, the Commission will examine those submissions in the light of the Convention. As regards the alleged violation of Article VI (right to a family and to protection thereof) of the American Declaration, the Commission considers that the petitioning party has not provided evidence or a sufficient basis for the Commission to conclude, *prima facie*, the possibility of the State having violated that Article to the detriment of the alleged victims.

17. With respect to the alleged violation of Article XI (right to the preservation of health and to well-being) of the American Declaration, the Commission considers that the facts adduced could, if they are corroborated as true, constitute violations of this Article. Bearing in mind that Article 26 of the Convention contains a general reference to economic, social, and cultural rights, and that they need to be determined in connection with the OAS Charter and applicable instruments, the Commission considers that in cases alleging

⁸ IACHR, Report N° 61/16, Petition 12,325. Admissibility. Comunidad de Paz San José de Apartadó. Colombia. December 6, 2016, par. 62; See also IACHR, Report No. 64/15, Petition 633-04. Admissibility. Mayan Peoples and members of the communities of Cristo Rey, Belluet Tree, San Ignacio, Santa Elena, and Santa Familia. Belize. October 27, 2015, par. 27.

⁹ See IACHR, Report No. 61/16, Case 12.325. Admissibility. Comunidad de Paz San José de Apartadó. Colombia. December 6, 2016, par. 62.

a specific violation of the Declaration related to the general content of the aforementioned Article 26, analysis of its relevance and identity pertains to the merits stage.

18. The Inter-American Commission lacks competence *ratione materiae* to pronounce, within its petitions procedure, on possible violations of the Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities and the International Covenant on Economic, Social and Cultural Rights. Nevertheless, pursuant to Article 29 of the American Convention, the Commission may take that treaty into account in its interpretation and enforcement of the American Convention and other applicable instruments.

19. The Court takes note that, since the last brief received from the petitioning party, the State has furnished information indicating progress reportedly made with compliance with the judgment of the Constitutional Court. The Commission has reviewed that information, but also takes into consideration that the petition alleges that the prolonged failure to comply with the judgment has caused irreparable harm to some of the alleged victims and that, from the information in the cases file, it does not transpire that the Constitutional Court has concluded its monitoring process and declared its judgment implemented. For those reasons, the Commission considers that the information provided by the State is insufficient to conclude that the wrongs adduced by the petitioning party have been effectively remedied, so an examination on the merits is still needed. That applies, without prejudice to an assessment of the information provided by the State being carried out at the merits stage.

VIII. DECISION

1. To declare the petition admissible as regards Articles 4, 5, 8, 9, 19, 24, 25, and 26 of the American Convention on Human Rights and Article XI of the American Declaration;
2. To declare this petition inadmissible in relation to Article VI of the American Declaration.
3. To notify the parties of this decision; to continue with the analysis on the merits, and to publish this decision and include it in its Annual Report to the General Assembly of the Organization of American States.

Approved by the Inter-American Commission on Human Rights on the 24th day of the month of April, 2020. (Signed): Joel Hernández, President; Antonia Urrejola, First Vice President; Flávia Piovesan, Second Vice President; Margarette May Macaulay, Esmeralda E. Arosemena Bernal de Troitiño, Julissa Mantilla Falcón, and Edgar Stuardo Ralón Orellana, Commissioners.

List of identified alleged victims

Children

1. Gabriel Alejandro Vasco Toapanta
2. Jefferson Steeven Reyes Zambrano
3. Mathyan Adrian Asanza Asanza
4. Jannick Miguel Castillo Castillo
5. Jorge Luis Romero Campoverde
6. Katheryn Mireya Ochoa Cedeño
7. Jonely Soledad Romero Loayza
8. María José Asanza Torres

Parents

1. Santiago Noe Vasco Morales
2. Irma Angelita Zambrano Torres
3. Christian Oswaldo Asanza Reyes
4. Rocío María Castillo Castro
5. Magali del Carmen Campoverde Añazco
6. Joahana Vanessa Cedeño Campoverde
7. Narciza Angelina Loayza Ayala
8. Irma Angelita Zambrano Torres