

**INTER-AMERICAN COMMISSION ON HUMAN RIGHTS
RESOLUTION 106/2021**

Precautionary Measure No. 306-21

N.V.E. regarding Colombia

December 24, 2021

Original: Spanish

I. INTRODUCTION

1. On April 9, 2021, the Inter-American Commission on Human Rights (“the Inter-American Commission,” “the Commission” or “the IACHR”) received a request for precautionary measures filed by Víctor Javier Mosquera Marín (“the applicant”), urging the Commission to require that the State of Colombia (“Colombia” or “the State”) adopt the necessary protection measures to guarantee the rights of 16-year-old adolescent N.V.E.¹ (“the proposed beneficiary”). According to the request, the proposed beneficiary faces a series of obstacles in accessing timely medical treatment, despite suffering from an incurable orphan disease.

2. Under the terms of Article 25 of the Rules of Procedure, the IACHR requested information from the parties on June 28, 2021. After a timeline extension was granted, the State provided information on July 12, 2021. The applicant submitted additional information on July 2, July 8, August 24, September 9, September 27, October 1, 2021, October 12, 2021, and November 9, 2021.

3. Upon analyzing the submissions of fact and law provided by the parties, the Commission considers that, from the *prima facie* standard, the proposed beneficiary is in a serious and urgent situation, given that her rights to life, personal integrity, and health face a risk of irreparable harm. Therefore, it requests that Colombia: a) adopt the necessary measures to protect the rights to life, personal integrity, and health of N.V.E. In particular, continue to guarantee that she has access to timely medical and psychological treatment, in accordance with the prescriptions and evaluations of competent physicians and under the applicable international standards, including those concerning intersex persons. These measures must be adopted in accordance with the prior, informed, and free consent of the beneficiary; and b) consult and agree upon the measures to be adopted with the beneficiary’s representation and the beneficiary, and if applicable, her father, mother, or guardian, considering her age.

II. SUMMARY OF FACTS AND ARGUMENTS PROVIDED BY THE PARTIES

1. Information from the applicant

4. The proposed beneficiary is a 16-year-old adolescent² (born on March 9, 2005) diagnosed with “classic congenital adrenal hyperplasia,” a salt-wasting variety, which is considered an incurable orphan disease, related to a genetic mutation that causes the suppression of the synthesis of aldosterone and cortisol, causing overstimulation of the adrenal glands and generating problems of regulation of blood pressure and regulation of body fluids. This overstimulation leads to the overproduction of androgens,

¹ The proposed beneficiary’s identity is kept confidential given that she is an adolescent. The State is aware of her identity following the forwarding of the request for precautionary measures and subsequent communications.

² As the present proceeding is *prima facie* in nature, the IACHR will use the language of “adolescent,” “girl,” or “she” insofar as this has been the language used by the parties when referring to the proposed beneficiary.

which can cause variations in sexual characteristics of individuals assigned to the female sex at birth. The applicant stated that N.V.E.'s situation is aggravated by the intersex presentation in her sexual characteristics.

5. It was indicated that, at birth, the girl had a neonatal seizure, and variations in the sexual characteristics of the disease, and she had to be hospitalized for two weeks. The medical condition of N.V.E. was diagnosed from birth; during her first two years of life, she underwent three corrective surgeries in her genitalia and urinary tract.³ The applicant stated that N.V.E. and her family are the victims of forced displacement in Colombia and completely depend on the State for access to health services.

6. The applicant explained that, since September 2013, N.V.E. has been affiliated with Capital Salud EPS, in a "subsidized regime."⁴ Due to the refusal of this health insurance to cover the expenses of her prescribed medications (hydrocortisone and fludrocortisone), the mother of N.V.E. indicated that she filed a request for protection of constitutional rights (*amparo*), with a favorable decision from the First Municipal Court of Small Causes and Multiple Competences on November 27, 2014, ordering that Capital Salud EPS "grant the request for comprehensive treatment to the minor (sic)." The applicant stated that N.V.E.'s mother filed "several appeals for contempt of court," and only on one occasion, on November 11, 2015, did the Court decide to open the appeal for contempt of court for non-compliance. According to the applicant, most of the contempt appeals were dismissed.

7. It was reported that in September 2015, October 2015, April 2016, August 2016, and February 2021, the proposed beneficiary was hospitalized in the emergency room due to the lack of her medications. In that sense, on September 8, 2020, she was examined by her endocrinologist, who issued an order for the delivery of hydrocortisone and fludrocortisone, noting in this order that these medications are of a "vital nature, and the lack of this medication [sic] endangers the life of the patient." Moreover, according to the applicant, on September 23, 2020, N.V.E.'s physician ordered consultations and medical examinations for a subsequent genital surgical procedure on the proposed beneficiary, taking into account "N.V.E.'s desire to start a full sexual life." In this sense, the applicant asserted:

[...] the minor [sic] stated in 2018 during a psychological consultation that her health situation was affecting her on an emotional level, as well as that she had expectations regarding the possibility of having a new surgery on her genitals, which is closely related to her imaginaries regarding her sexuality and her motherhood project. Similarly, during the consultation with the urologist in 2020, precisely when the surgery orders were issued, [N.V.E.] expressed her desire to start a full sexual life and expressed her wish to undergo surgery.

8. However, on January 29, 2021, N.V.E.'s mother received a negative response from Capital Salud EPS regarding medical procedures "because there is no agreement that allows them to be carried out." According to the applicant, on April 23 and 26, 2021, N.V.E.'s mother received other refusals for an appointment with a pediatric coloproctology specialist.

9. The applicant stated that on October 1, 2020, the mother of N.V.E. filed the request for authorization of the medications ordered, but that she received a call from Capital Salud on January 29, 2021, informing her that the delivery of the medications had been denied. It was indicated that the

³ On January 28, 2006, she underwent surgery for feminizing genitoplasty, reduction clitoridoplasty, and closure of urethrovaginal fistula. On March 9, 2006, she underwent urethral and vaginal dilatation. On March 23, 2007, she underwent "labia minora correction surgery" and cystoscopy.

⁴ The Subsidized Regime is the mechanism by which the poorest population, without the ability to pay, has access to health services through a subsidy offered by the State.

proposed beneficiary's mother carried out different steps to achieve the delivery of the medications, while only fludrocortisone (50 tablets, treatment for one month and 20 days) was delivered on February 6, 2021. Due to this, the applicant indicated that on February 19, 2021, N.V.E. was hospitalized to stabilize her symptoms of dizziness and nausea, which occurred due to the lack of access to her "vital medications" for more than a month. Upon being assessed, on February 20, 2021, the physician from the Hospital de la Misericordia determined that there would be a risk of an adrenal crisis, which, according to the applicant, may cause "states of shock or even death." After a week of hospitalization, the medications were finally delivered, and the proposed beneficiary was discharged.

10. On April 20, 2021, N.V.E. was urgently admitted to the Hospital de La Misericordia and had to receive a blood transfusion "after suffering serious hemorrhage" that "was caused by an infectious process that had to be studied." On that occasion, N.V.E.'s mother stated at the hospital that Capital Salud has not yet complied with the last order for the delivery of fludrocortisone and hydrocortisone, whose medical order reportedly expire on April 24, 2021, under the argument of the EPS that "it was having problems in the system, which is why there were purported delays in the service." N.V.E.'s father went to Capital Salud to obtain information on the delivery of the medicines, and the EPS reported that "it would do the situation report again." In this sense, "given the possibility that N.V.E. was hospitalized for the non-administration of the drugs, the treating physicians managed to deliver them" and N.V.E. was discharged on April 23, 2021.

11. The applicant reported difficulties imposed by the EPS for N.V.E. to be examined by a specialist in coloproctology, which was required so that the proposed beneficiary can undergo the next surgery. On the other hand, the applicant indicated that on April 26, 2021, the mother of the proposed beneficiary tried to schedule examinations and medical appointments after the N.V.E.'s hospitalization that required a blood transfusion. However, the EPS "indicated that it would not carry out the scheduling of these medical procedures" because it did not have an agreement with the Hospital de la Misericordia, and that what N.V.E. suffered "was a simple urinary infection," unrelated to her orphan disease. Therefore, on May 1, 2021, N.V.E.'s mother filed a complaint with the Superintendency of Health.

12. According to the applicant, on May 4, 2021, N.V.E. underwent an ultrasound, identifying the existence of a uterine polyp, which is why she required an urgent surgical procedure "since it was very probable that the polyp was generating bleeding and the last symptoms that she has been suffering from." It was highlighted that on May 6, 2021, N.V.E. was examined by an endocrinologist who reported that the ultrasound showed "serious problems, which is why it was necessary for the gynecologist to see her urgently," and that the uterine polyp "can even lead to uterine cancer or danger of death." In this regard, he stated that N.V.E. should continue with the drugs hydrocortisone, fludrocortisone, tranexamic acid, and ethinyl estradiol + levonorgestrel.

13. It was noted that on May 14, 2021, N.V.E. had an appointment with the gynecologist, who warned the mother that the proposed beneficiary "was presenting with new symptoms, probably related to her orphan disease," and that therefore "it was necessary to carry out the urgent surgical procedures of perineal vaginoplasty, feminizing ambiguous genitalia surgery, and total skin graft in a special area of the genitalia." According to the applicant, the specialist indicated that, if this procedure is not performed "immediately, her state of health would deteriorate over time."

14. According to the applicant, the vaginoplasty surgical procedure has not been performed so far, even though, as indicated, this is an urgently required procedure since September 2020. Moreover, on June 17, 2021, the proposed beneficiary allegedly underwent a hysteroscopy and endometrial biopsy, confirming the diagnosis of "polyp of the body of the uterus." According to the applicant, "uterine

endometrial polyps tend to appear when there are hormonal imbalances [...], this being one of the main consequences of congenital adrenal hyperplasia.”

15. It was noted that on June 29, 2021, the proposed beneficiary attended a medical appointment with an endocrinology specialist who established in their report “genital malformation secondary to congenital adrenal hyperplasia, currently with vaginal stenosis”; “she requires follow-up in an institution with urology, gynecology, laparoscopy, coloproctology, and pediatric endocrinology, to hold a meeting regarding the treatment of this lesion”; “menstrual cycle altered by metrorrhagia”; “primary adrenal insufficiency”; “depression, suspected dysphoria.” In this sense, the specialist stressed that lately the proposed beneficiary “has inquired about gender dysphoria, wants to remove her uterus, wants to remove her breasts, wants to cut her hair.” The applicant indicated that on June 29, 2021, N.V.E. underwent a control by the psychiatry specialist, who indicated in the medical diagnosis that N.V.E. “has depressive episodes related to her illness, for which she was medicated with fluoxetine 20 mg per day.” The mother of the proposed beneficiary filed multiple complaints against Capital Salud before the Superintendency of Health, and that, even though, no action had been taken. Due to this, in June 2021, N.V.E.’s mother made the case public through a media outlet.

16. It was indicated that the medical orders of June 11 and 29, 2021, for the delivery of “Ethinyl estradiol [and] drospirenone” had not been fulfilled. Neither was the order for “Hydrocortisone 10 MG” dated March 9, 2021, and the order for the delivery of dermatological drugs, “Minoxidil 5%,” “Piloskin anti-hair loss-antiseptic”; Children sunscreen; “Lubriderm moisturizing cream,” dated May 6, 2021. According to the applicant, the dermatological drugs were ordered for the treatment of atopic dermatitis and androgenic alopecia, generated by the orphan disease that N.V.E. suffers from; however, the authorization for the delivery has been pending for months, because the EPS argues that these drugs are not part of the treatment of the orphan disease suffered by the proposed beneficiary. On July 8, 2021, the applicant indicated that, in the same week, EPS Capital Salud has contacted N.V.E.’s mother “for the possible scheduling of medical appointments and performance of surgical procedures.” The Superintendency of Health also contacted N.V.E.’s mother “in order to state that this entity is following up on her daughter’s case.” However, the applicant affirmed that the medications ordered by the dermatologist have not been delivered, the surgical procedures have not been authorized, “nor has the appointment with the different specialists been scheduled, including gynecology.”

17. According to the applicant, on May 24, 2021, the Twenty-fifth Court of Small Causes of Kennedy launched the contempt appeal within the framework of the aforementioned ruling on protection of constitutional rights (*amparo*). On August 5, 2021, EPS Capital Salud brought its response to the Court, in which it reported that on May 24, 2021, it delivered 100 hydrocortisone tablets and 50 fludrocortisone tablets. However, the applicant reported on August 24, 2021, that Capital Salud’s response is “incomplete and misleading,” since the amount of the drugs is “much lower than those ordered by physicians,” considering that N.V.E. must take three pills of hydrocortisone daily and a fludrocortisone pill daily and that medical orders are issued for a total of six months. Moreover, it was stated that the EPS has left “out the medical appointments with specialists and other medications that N.V.E. requires to obtain a comprehensive health treatment.”

18. In addition, the applicant indicated that on August 4, 2021, N.V.E. had a consultation with the pediatric surgeon of Hospital La Misericordia and on this occasion the physician indicated that this institution does not have a gynecology service and referred her to Hospital San José. However, according to the applicant, the EPS Capital Salud has insisted on sending her to be treated at La Misericordia Hospital, “which has resulted in a great obstacle, since this entity’s physicians have told her that they cannot treat her and much less perform the surgeries she needs.” The applicant also reported that the proposed beneficiary is waiting for the EPS to authorize the holding of an urgent medical meeting “in

order to evaluate her condition, as well as the authorization of the delivery of a dilator device whose use is a prerequisite for the performance of the surgeries that the minor (sic) requires by order of her physicians.”

19. The applicant stated that “it has been necessary to bring at least four additional memorials to the court” hearing the contempt appeal, in order to report new breaches of the *amparo* ruling. The contempt appeal filed in February 2021 has not yet been resolved, while, to date, EPS Capital Salud has not answered a request for information from the Twenty-fifth Court of Small Causes and Multiple Jurisdiction of Kennedy dated November 5, 2021. The applicant indicated that the EPS refused to authorize the holding of an interdisciplinary medical meeting to study the case of N.V.E., rejected the request for delivery of “a tool known as a ‘dilator’”; that, to date, EPS Capital Salud has not delivered dermatological medications to treat atopic dermatitis and androgynous alopecia that N.V.E. suffers from; and that the delivery of “vital drugs” to the proposed beneficiary “has always been intermittent.” In relation to this last point, the applicant stated that the last delivery of the hydrocortisone drug was on October 14, 2021, and that the adolescent has not received it for over a month.

2. Response from the State

20. The State indicated that the existence of compliance with the requirements of Article 25 of the Rules of Procedure has not been demonstrated. In that sense, it affirmed that Salud Capital EPS has deployed the management actions for the provision of health services in favor of the proposed beneficiary and that the National Superintendency of Health has constantly monitored the procedures deployed by the EPS. The State provided information on the particular situation of the proposed beneficiary, consisting of reports prepared by the National Superintendency of Health (Supersalud) and by the Health Promotion Entity (EPS), Salud Capital EPS.

21. Supersalud detailed the service required with the corresponding medications and benefits, listing the complaints filed and the status. Specifically, nine complaints are exposed (November 7, 2017; August 6, September 10, November 24, 2020; February 5, May 3, May 18, July 2, and July 6, 2021), all due to the lack of delivery of medications and appointment assignments, one of them including the refusal to “perform an ultrasound examination of the urinary tract.” According to the complaints related by Supersalud in its report, only the last of them has a status “in process,” dated July 6, 2021, while the remaining ones have a status of “closed.” Moreover, Supersalud reported that “a response was received on July 6 from Capital Salud reporting the latest medical record, delivery of medications and medical consultations” and that “information was confirmed with the user’s mother indicating following check-up appointment in September, pending assessment by adolescent gynecology ordered by the San Ignacio Hospital, May 14, 2021, [and] dermatological supplies [...]”

22. For its part, the EPS indicated that the proposed beneficiary has been affiliated with Capital Salud EPS-S in a subsidized regime since November 8, 2013, and that she has a diagnosis of “congenital adrenal hyperplasia (orphan disease according to Resolution 5265 of 2018).” Capital Salud’s medical-technical team provided general information about the disease, its clinical manifestations, and its treatment, which can be divided into medical treatment with steroids and salt and surgical treatment. Among the clinical manifestations, the State noted:

[...] saline loss: she presents clinical manifestations from birth. When there is a total deficiency of aldosterone, there will be a hydroelectrolytic disorder due to the inability to retain sodium and water and excrete potassium, and there may exist hyperkalemia (increased potassium), hyponatremia (increased sodium), and metabolic acidosis, which are manifested with inappetence (loss of appetite), lethargy (lack of energy, weakness), vomiting, diarrhea, polyuria (increased urinary frequency),

dehydration, weight loss, hypotension, and in severe cases hypovolemic shock. Congenital Adrenal Hyperplasia (CAH) is not curable, its treatment is palliative for life, and what is done is to replace hormonal deficiencies with synthetic hormones in the form of tablets (we replace the hormones that the adrenal gland does not produce: cortisol and aldosterone).

23. In this sense, the EPS detailed the authorization dates for the supply of medicines in 2020 (October and November authorization of hydrocortisone and fludrocortisone; December authorization of hydrocortisone) and 2021 (January, authorization of fludrocortisone carried out on February 4; month February authorization of hydrocortisone; month March authorization of hydrocortisone; month April authorization of hydrocortisone and fludrocortisone; month May authorization of hydrocortisone and fludrocortisone; month June authorization of hydrocortisone and fludrocortisone). However, the EPS reported that they had “internal administrative problems,” which “logistically made it difficult for providers to prescribe” the drug hydrocortisone and that “although it is true that for this period there were logistical difficulties with our drug supplier, it is also true that [...] N.V.E. [...] has not run out of the hormonal supply corresponding to the two hormones simultaneously.” Moreover, it stated that, given that hydrocortisone is short-acting, and fludrocortisone is intermediate-acting, “one supplements the other and guarantees prolonged treatment over time.”

24. The EPS reported that there is an *amparo* ruling dated November 27, 2014, filed for the supply of the drugs hydrocortisone and fludrocortisone, in which “the judge denied, as overcome fact, the request in the *amparo* required at the time of the provisional measure,” although it granted comprehensive treatment for the management of the adrenal hyperplasia pathology” of the proposed beneficiary. In addition to this, it reported that there was a formal opening of an appeal for contempt of court notified to the EPS on May 24, 2021, also indicating that the legal proceeding had been closed since June 12, 2018 and that, following the opening of the new proceeding, it had contacted the proposed beneficiary’s mother, who reported that “she filed the appeal for contempt of court for the non-delivery of the medications hydrocortisone and fludrocortisone.” In that sense, it reported having carried out “the corresponding follow-up, finding that the medications were delivered on May 26, 2021,” which was reported to the judicial office on May 28, 2021.

25. Regarding the surgical procedure, the EPS indicated that “the scarcity in the offer of pediatric coloproctology and pediatric urology specialties and the difficulty to manage a comprehensive treatment in a single institution with pediatric specialties in our contracted network.” Therefore, they carried out “an advance payment procedure with the IPS Hospital San Ignacio” for consultations that took place on September 23, 2020. The EPS reported that they sent the proposed beneficiary to the IPS Hospital San José Sociedad de Cirugía de Bogotá, “because this entity performs reconstructive plastic surgery of female genitalia, but [...] the hospital [...] refers that this procedure must be performed in an institution with pediatric specialties.” Therefore, the EPS made “an approach with the La Misericordia hospital, in such a way that comprehensive care is provided for the medical and surgical management” of the disease suffered by N.V.E. In that sense, on July 1, 2021, the La Misericordia hospital contacted the mother of the proposed beneficiary “to inform her of the appointment scheduled for 08/04/2021 [...] and start a comprehensive care protocol and surgical medical management.”

26. Similarly, the EPS emphasized that it guaranteed all the services required while the proposed beneficiary was hospitalized in February and April 2021, being that “it is not entirely true that the reason for the hospitalization was the illness suffered by the minor (sic), because upon reviewing the medical record it is found that she was hospitalized for a febrile syndrome secondary to a urinary tract infection [...]”

III. ANALYSIS OF THE ELEMENTS OF SERIOUSNESS, URGENCY, AND IRREPARABLE HARM

27. The mechanism of precautionary measures is part of the Commission's function of overseeing compliance with the human rights obligations set forth in Article 106 of the Charter of the Organization of American States. These general oversight functions are established in Article 41(b) of the American Convention on Human Rights, as well as in Article 18(b) of the Statute of the IACHR. The precautionary measures mechanism is described in Article 25 of the Commission's Rules of Procedure. In accordance with that Article, the Commission grants precautionary measures in serious and urgent situations in which these measures are necessary to avoid an irreparable harm to persons.

28. The Inter-American Commission and the Inter-American Court of Human Rights ("the Inter-American Court" or "I/A Court H.R.") have repeatedly established that precautionary and provisional measures have a dual nature, both protective and precautionary.⁵ Regarding the protective nature, these measures seek to avoid irreparable harm and protect the exercise of human rights.⁶ To do this, the IACHR shall assess the problem raised, the effectiveness of state actions to address the situation described, and how vulnerable the persons proposed as beneficiaries would be left in case the measures are not adopted.⁷ Regarding their precautionary nature, these measures have the purpose of preserving legal situations while under the consideration of the IACHR. The precautionary nature aims at safeguarding the rights at risk until the petition pending before the inter-American system is resolved. Their object and purpose are to ensure the integrity and effectiveness of an eventual decision on the merits and, thus, avoid any further infringement of the rights at issue, a situation that may adversely affect the useful effect (*effet utile*) of the final decision. In this regard, precautionary or provisional measures enable the State concerned to comply with the final decision and, if necessary, to implement the ordered reparations.⁸ In the process of reaching a decision, according to Article 25(2) of its Rules of Procedure, the Commission considers that:

- a. "serious situation" refers to a grave impact that an action or omission can have on a protected right or on the eventual effect of a pending decision in a case or petition before the organs of the inter-American system;
- b. "urgent situation" refers to risk or threat that is imminent and can materialize, thus requiring immediate preventive or protective action; and

⁵ See in this regard: I/A Court H.R. [Matter of the Yare I and Yare II Capital Region Penitentiary Center](#). Request for Provisional Measures submitted by the IACHR regarding the Bolivarian Republic of Venezuela. Order of the Inter-American Court of Human Rights of March 30, 2006, considerandum 5; I/A Court H.R. [Case of Carpio Nicolle et al. v. Guatemala](#). Provisional Measures. Order of July 6, 2009, considerandum 16.

⁶ See in this regard: I/A Court H.R. [Matter of Capital El Rodeo I and El Rodeo II Judicial Confinement Center](#). Provisional Measures regarding Venezuela. Order of the Court of February 8, 2008, considerandum 8; I/A Court H.R. [Case of Bámaca Velásquez](#). Provisional Measures regarding Guatemala. Order of the Court of January 27, 2009, considerandum 45; I/A Court H.R. [Matter of Fernández Ortega et al.](#) Provisional Measures regarding Mexico. Order of the Court of April 30, 2009, considerandum 5; I/A Court H.R. [Matter of Milagro Sala](#). Request for Provisional Measures regarding Argentina. Order of the Inter-American Court of Human Rights of November 23, 2017, considerandum 5 [only in Spanish].

⁷ See in this regard: I/A Court H.R. [Matter of Milagro Sala](#). Request for Provisional Measures regarding Argentina. Order of the Inter-American Court of Human Rights of November 23, 2017, considerandum 5 [only in Spanish]; I/A Court H.R. [Matter of Capital El Rodeo I and El Rodeo II Judicial Confinement Center](#). Provisional Measures regarding Venezuela. Order of the Court of February 8, 2008, considerandum 9; I/A Court H.R. [Matter of the Criminal Institute of Plácido de Sá Carvalho](#). Provisional Measures regarding Brazil. Order of the Inter-American Court of Human Rights of February 13, 2017, considerandum 6 [only in Spanish].

⁸ See in this regard: I/A Court H.R. [Matter of Capital El Rodeo I and El Rodeo II Judicial Confinement Center](#). Provisional Measures regarding Venezuela. Order of the Court of February 8, 2008, considerandum 7; I/A Court H.R. [Matter of "El Nacional" and "Así es la Noticia" newspapers](#). Provisional Measures regarding Venezuela. Order of the Court of November 25, 2008, considerandum 23; I/A Court H.R. [Matter of Luis Uzcátegui](#). Provisional Measures regarding Venezuela. Order of the Court of January 27, 2009, considerandum 19.

- c. “irreparable harm” refers to injury to rights which, due to their nature, would not be susceptible to reparation, restoration or adequate compensation.

29. In analyzing these requirements, the Commission reiterates that the facts supporting a request for precautionary measures need not be proven beyond doubt. However, a minimum of detail and information is required to determine, from a *prima facie* standard of review, whether a serious and urgent situation exists pursuant to Article 25 of the Rules of Procedure.⁹

30. When analyzing the procedural requirements, the Commission considers that intersectional factors of vulnerability are present in the case of the proposed beneficiary. From the information provided by the parties, the Commission understands that N.V.E. is an adolescent, safeguarded at the international level by the standards against violence against women, girls, and adolescents. Besides, as a 16-year-old adolescent, any measure to be adopted must have as a primary consideration her best interests.¹⁰ The Inter-American Court has indicated that the “best interests” constitutes the “[...] reference point to ensure effective realization of all rights contained in [the Convention on the Rights of the Child], their observance will allow the subject to fully develop his or her potential.”¹¹ Moreover, the due protection of the rights of children and adolescents must consider the principle of progressive autonomy and “take into consideration their own characteristics and the need to promote their development.”¹²

31. Similarly, it has been indicated that she suffers from an orphan disease from birth, called “congenital adrenal hyperplasia,” which is incurable, and requires palliative treatment for life (see *supra* paras. 4 and 21). The Commission also observes, based on what was indicated by the applicant, that, N.V.E. was born with a variation in her genital organs with respect to the culturally prevailing standard of feminine or masculine corporeality¹³; hence, after her birth, she underwent various surgeries on the genitalia and urinary tract (see *supra* para. 5). Considering that the applicants emphasized her intersex situation, the Commission recalls that the term “intersex” has been developed to describe all those situations in which a person’s body does not appear to conform to society’s binary “standard” of corporeality. This may become visible at birth, during childhood, adolescence or, in some specific cases, at no time in their lives.¹⁴ In a similar sense, the Inter-American Court understands that it refers to the following:

⁹ See in this regard, I/A Court H.R. [Matter of Members of the Miskitu Indigenous Peoples of the North Caribbean Coast regarding Nicaragua](#). Extension of Provisional Measures regarding Nicaragua. Order of the Inter-American Court of Human Rights of August 23, 2018, considerandum 13 [only in Spanish]; I/A Court H.R. [Matter of Children Deprived of Liberty in the “Complexo do Tatuapé” of the Fundação CASA](#). Request for extension of provisional measures. Provisional Measures regarding Brazil. Order of the Inter-American Court of Human Rights of July 4, 2006. Considerandum 23.

¹⁰ Convention on the Rights of the Child, Art. 3. 1. 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. 2. States Parties undertake to ensure the child such protection and care as is necessary for his or her well-being, taking into account the rights and duties of his or her parents, legal guardians, or other individuals legally responsible for him or her, and, to this end, shall take all appropriate legislative and administrative measures. 3. States Parties shall ensure that the institutions, services, and facilities responsible for the care or protection of children shall conform with the standards established by competent authorities, particularly in the areas of safety, health, in the number and suitability of their staff, as well as competent supervision. Available at <https://www.ohchr.org/en/professionalinterest/pages/crc.aspx>

¹¹ I/A Court H.R., Advisory Opinion OC-17/2002 of August 28, 2002, *Juridical Condition and Human Rights of the Child*, paragraph 59. Available at https://www.corteidh.or.cr/docs/opiniones/seriea_17_ing.pdf

¹² I/A Court H.R. Advisory Opinion OC-24/2017, para. 150.

¹³ See in this regard: <https://www.oas.org/es/cidh/jsForm/?File=/es/CIDH/r/DLGBTI/precisiones.asp>

¹⁴ IACHR, Press Release No. 256/20, On International Intersex Awareness Day, the IACHR Calls on States to Protect the Right to Health of Intersex Persons, October 26, 2020.

[...] An intersex person is born with a sexual anatomy, reproductive organs, or chromosome patterns that do not fit the typical definition of a man or woman. This can be apparent at birth or become apparent over the years. An intersex person can identify themselves as male or female or neither. Intersex status is not about sexual orientation or gender identity: intersex people experience the same range of sexual orientations and gender identities as non-intersex people.¹⁵

32. In the same way, the IACHR underscores her situation as a victim of forced displacement and that, given her financial situation, she is enrolled in a health insurance regime that is subsidized by the State (see *supra* para. 21), which is applied in favor of the population in poverty without the ability to pay (see *supra* para. 5 and footnote 2). Specifically, the provision of health services is allegedly in charge of Capital Salud EPS since 2013 (see *supra* paras. 6 and 19).¹⁶ In this regard, the applicant indicated that N.V.E. and her family depend “completely” on the State to access health services (see *supra* para. 5).

33. The Commission herein performs the analysis of the procedural requirements within the framework of the previous considerations, which are sufficient to understand the current situation of the proposed beneficiary, as well as the situation of intersectional vulnerability that she faces. The Commission notes, when analyzing the requirement of *seriousness*, that the disease suffered by N.V.E. is incurable and requires palliative medical treatment, which ranges from steroids and salt. Among the most serious cases that can arise as a complication of the disease is hypovolemic shock (see *supra* para. 21). Besides, as indicated by the applicant, the disease also requires surgical treatment, as prescribed by the competent physicians.

34. The Commission notes that the applicants indicated that the proposed beneficiary has the “classic” variety of the disease (see *supra* para. 4), which reportedly caused her a variation in her sexual anatomy since birth. According to medical entities, the classic form of the disease is more serious.¹⁷ Moreover, individuals assigned to the female sex at birth and present this condition may have elongated clitoris or genitalia more similar to that of individuals assigned to male sex at birth.¹⁸ All persons with hyperplasia can be seriously affected by a lack of cortisol, aldosterone, or both, which is known as a life-threatening adrenal crisis.¹⁹ In the particular case of the proposed beneficiary, the Commission observes that the following medical examinations and prescriptions were initially made:

- On September 8, 2020, after being examined by endocrinology, she was prescribed the medications hydrocortisone and fludrocortisone. The medical order purportedly indicates that these are “vital” drugs and their lack “endangers the life of the patient” (see *supra* para. 7).
- On September 23, 2020, a physician ordered consultations and medical examinations for a subsequent surgical procedure to modify N.V.E.’s sexual characteristics due to the intention manifested by N.V.E. to start a sexual life and her “maternity project” (see *supra* para. 7).

35. The Commission notes that the representation has indicated that the prescribed hydrocortisone and fludrocortisone medications are not being delivered in a timely manner, which purportedly led to family members filing a series of complaints (see *supra* para. 20). In this sense, a refusal in the delivery of such drugs is not properly observed, but a delay in their delivery. In this regard, the State indicated

¹⁵ I/A Court H.R., Advisory Opinion OC-24/2017, para. 32.

¹⁶ I/A Court H.R. Case of Vera Rojas *et al.* v. Chile. Judgment of October 1, 2021. Preliminary Objections, Merits, Reparations, and Costs, para. 89: [...] States must regulate and supervise all activities related to the health care given to the individuals under the jurisdiction thereof, as a special duty to protect life and personal integrity, regardless of the public or private nature of the entity giving such health care. The obligation of the State is not limited to hospitals that provide public services but encompasses any and all health institutions.

¹⁷ Available at <https://www.mayoclinic.org/es-es/diseases-conditions/congenital-adrenal-hyperplasia/symptoms-causes/syc-20355205>

¹⁸ *Ibidem*

¹⁹ *Ibidem*

that there were “internal administrative problems,” which has not implied that the proposed beneficiary was left without “hormonal supply of the two hormones simultaneously” (see *supra* para. 22). For its part, the representation indicated that the delivery is not complete (see *supra* para. 16). In view of the allegations, the Commission observes that it does not have the necessary elements to be able to analyze whether, in medical terms, such drugs are sufficient or not for the proposed beneficiary. However, it does find that the deliveries of the drugs prescribed to treat the orphan disease of the proposed beneficiary have been carried out with time delays, at least this year so far (see *supra* para. 18). Consequently, this has led to complaints being filed with the competent entities, considering that medical orders expire in time. For the Commission, this delay is worrisome, as such drugs are considered “vital” for the palliative treatment of the proposed beneficiary in the conditions in which she currently finds herself. This situation has an impact on the ongoing medical treatment prescribed by the medical staff and influences the analysis of the seriousness of her situation, especially considering that the applicants indicate that the delay in the delivery of the last month persists (see *supra* para. 18).

36. With respect to the remaining prescribed drugs, the Commission does not have sufficient assessment elements to identify how the lack of their delivery is related to the proposed beneficiary’s medical situation and her orphan disease, pursuant to Article 25 of the Rules of Procedure (see *supra* paras. 15 and 18). Regarding the hospitalization in February and April 2021, the State indicated that “she was hospitalized for a febrile syndrome secondary to a urinary tract infection,” and therefore, it was not related to the disease she suffers from (see *supra* paras. 10 and 25). For its part, the representation understands that this occurred in the absence of delivery of the prescribed medications that are considered “vital” (see *supra* paras. 8 and 9). In this regard, the Commission notes that even considering that it is an issue related to a urinary tract infection, such medical situations required hospitalization and occurred at times when the delivery of drugs considered “vital” was pending, being that in February 2021, a risk of an “adrenal crisis” was warned that could generate shock or death, and in April 2021, a “serious hemorrhage” occurred (see *supra* paras. 8 and 9). This clarification is relevant inasmuch as it has been reported that one of the clinical manifestations of the orphan disease is an increase in urinary frequency (see *supra* para. 21).

37. Moreover, the following observations concerning the medical record and health status of N.V.E. are noted:

- On May 4, 2021, the possible existence of a uterine polyp was identified, and an “urgent” surgical procedure was recommended. According to the applicant, it was indicated that it was possible that this polyp was causing her bleeding and the symptoms that she had been suffering up to that moment (see *supra* para. 11).
- On May 6, 2021, an ultrasound revealed “serious problems, which is why it was necessary for the gynecologist to see her urgently,” and that the uterine polyp “can even lead to uterine cancer or danger of death” (see *supra* para. 11).
- On May 14, 2021, “new symptoms probably related to her orphan disease” were indicated, and that “it was necessary to urgently perform surgical procedures of perineal vaginoplasty, feminizing ambiguous genitalia surgery, and total skin graft in a special area on genitals” (see *supra* para. 12). According to the applicant, if not performed immediately, her health would deteriorate.
- On June 17, 2021, the diagnosis of “polyp of the body of the uterus” was confirmed. According to the applicant, it is related to the hormonal imbalances of the disease (see *supra* para. 13).
- On June 29, 2021, a psychiatrist indicated that N.V.E. “has depressive episodes related to her illness, for which she was medicated with fluoxetine 20 mg per day” (see *supra* para. 14).

38. Thus, the Commission also notes that the proposed beneficiary was also diagnosed with a “uterine polyp” that was classified as a “serious problem” that could lead to uterine cancer or danger of death, prescribing “urgent” surgical procedure in the face of new symptoms that may be related to her orphan disease. In this regard, the Commission observes that, according to the information provided by the parties, the surgical procedure had not been performed to date either. As regards the scheduling of the surgery to modify the sexual characteristics of the proposed beneficiary, the Commission notes that this was recommended in September 2020 and has not been performed so far.

39. The information available is not sufficient to indicate that the Hospital that may finally attend to her as regards the surgical issue has been defined (see *supra* para. 17), or whether the required medical meeting had been held to assess her situation has been held (see *supra* para. 17). Given that the aforementioned meeting is still pending, the Commission considers it important to recall that the State must consider the particular situation of the proposed beneficiary, taking into account at all times the best interests of the adolescent and allowing her participation in the exercise of her autonomy, and that she must have sufficient knowledge of all the consequences derived from the medical treatment and surgical procedures recommended to her.

40. In line with the foregoing, in general terms, and by way of thematic background, the Commission has been informed that, during medical procedures on intersex persons, intersex children are often subjected to abusive exposures, as well as repetitive examinations for scientific or training purposes, which constitute humiliating treatment and may cause them profound psychological harm.²⁰ In fact, the Commission observes in N.V.E.’s medical record that the proposed beneficiary had appointments with multiple physicians in the last few years, in different health care institutions, including those where it has been alleged that they did not have the technical conditions to treat her. Therefore, the Commission notes, in line with the medical recommendations of the physicians who have examined the proposed beneficiary, that it is urgent to create an interdisciplinary team to assess the treatment of the proposed beneficiary, taking into account her medical record and considering the risk faced by N.V.E.²¹

41. The Commission notes with concern that, on June 29, 2021, it was also identified that she purportedly suffers from depressive episodes. Although it was indicated that she is receiving psychiatric care, the Commission has emphasized the need to adopt comprehensive health protocols that address the specific needs of intersex people, including as a priority attention to their mental health.²² The Commission stresses as well that the adolescent was referred to psychiatric consultation due to suspected gender dysphoria (see *supra* para. 15). In broad terms, the IACHR notes that this concept can be used to perpetuate the pathologizing notion of gender identities that are not included in cisnormativity.²³

²⁰ IACHR, Violence against Lesbian, Gay, Bisexual, Trans and Intersex Persons in the Americas, para. 186.

²¹ Regarding the interdisciplinary team, the IACHR recalls, in general terms and as thematic background, that the IACHR has called on States to train medical personnel and the medical community to provide adequate treatment and support for intersex persons and their families, as well as to take measures to support intersex persons and their families through interdisciplinary teams during all stages of development from infancy, through childhood and adolescence, and into adulthood. See in this regard: IACHR, Violence against Lesbian, Gay, Bisexual, Trans and Intersex Persons in the Americas, Rec. 56.

²² IACHR, [On International Intersex Awareness Day, the IACHR Calls on States to Protect the Right to Health of Intersex Persons](#), October 26, 2020.

²³ See in this regard: *Amicus curiae*, Request for Advisory Opinion No. 24, filed by the State of Costa Rica before the Inter-American Court of Human Rights. [Observations of 16 human rights organizations that are part of the Coalition of LGBTTTI Organizations before the OAS](#), February 14, 2017, para. 42; IACHR, [Report on Trans and Gender Diverse Persons and their Economic, Social, Cultural and Environmental Rights](#), August 7, 2020, para. 43.

42. The above shows the need for N.V.E. to receive comprehensive care with a human rights perspective, which may include N.V.E. learning about concepts of intersexuality as well as differences and intersections with concepts of gender identities, including diverse gender identities from a perspective of acceptance and inclusion, in an environment free of discrimination, so that she can participate in medical decision-making independently of prejudices and stigmas about bodily diversity.²⁴

43. On another note, the Commission has stressed that “intersex people are exposed to specific forms of violence from childhood and adolescence, in a context of invisibility, prejudice, and taboos,”²⁵ including the performance of surgeries and procedures –mostly unnecessary from a medical point of view–, which cause enormous damage,²⁶ particularly during childhood and adolescence, without their informed consent, for the purpose of making aesthetic modifications.²⁷ Although the applicant has affirmed that the adolescent has manifested before different medical professionals her interest in undergoing the prescribed surgeries, in view of her desire to “start a full sexual life” and her “maternity project” (see *supra* para. 7), the Commission does not ignore the fact that N.V.E. has undergone surgeries since birth, including feminizing genitoplasty, and reduction clitoridoplasty, as well as vaginal dilation. The IACHR notes that, recently, consultations and medical examinations were ordered for an eventual future surgical procedure to modify again the sexual characteristics of the proposed beneficiary. In this regard, the Commission notes that the principle of free, prior, and informed consent is of the utmost importance and should guide all decisions related to surgeries, procedures, hormonal treatments and any other medical treatment for intersex persons.²⁸ In this sense, the preamble of the Yogyakarta Principles notes that “in all actions concerning children, it will be the best interest of the child, and that a child who is in a position to form a judgment about their own person, has the right to express their opinion freely in all matters that affect them [...] based on their age and maturity.”²⁹

44. The Inter-American Court of Human Rights has established that “in the case of children, although they are subjects of human rights, they exercise their rights progressively as they develop a greater level of personal autonomy.” Moreover, the Court has indicated that “the right of each person to autonomously define their sexual and gender identity is protected by the American Convention.”³⁰ In line with the above, the Commission deems that the identity, age, and progressive autonomy of the proposed beneficiary represent aspects to be considered in assessing the situation that she is currently facing, as well as for the specialists to determine, with full guarantee of free, prior, and informed consent, the treatment that she would require.

²⁴ The IACHR has called on States to adopt strategies to ensure the effective communication and transfer of adequate information to intersex persons and their families about the consequences of surgical and other medical interventions, with a perspective of cultural and linguistic relevance. See in this regard: IACHR, On International Intersex Awareness Day, the IACHR calls on States to guarantee the right to health of intersex persons, October 26, 2020.

²⁵ The IACHR has indicated that surgeries on intersex children should be postponed until the person in question is able to give their free, prior, and informed consent, and has called on States to prohibit medical interventions on intersex children and adolescents that are not medically necessary when performed without their free, prior, and informed consent. See in this regard: IACHR, Violence against LGBTI persons, 2015, recommendation 81; IACHR, [IACHR Calls on States to Guarantee the Right to Truth, Justice, and Reparation for Intersex People](#), October 26, 2021.

²⁶ IACHR, [Violence against Lesbian, Gay, Bisexual, Trans, and Intersex Persons in the Americas](#), para. 186.

²⁷ IACHR, [On International Intersex Awareness Day, the IACHR Calls on States to Protect the Right to Health of Intersex Persons](#), October 26, 2020. See also: IACHR, [Hearing about the situation of human rights intersex persons in the Americas](#), 147th Period of Sessions, March 15, 2013.

²⁸ IACHR, [Violence against Lesbian, Gay, Bisexual, Trans, and Intersex Persons in the Americas](#), para. 194.

²⁹ Yogyakarta Principles. [Principles on the Application of International Human Rights Law in Relation to Sexual Orientation and Gender Identity](#), Yogyakarta, Indonesia, November 2006, preamble, p. 9.

³⁰ I/A Court H.R., Vicky Hernández *et al.* v. Honduras. Judgment of March 26, 2021. Merits, Reparations, and Costs, para. 115.

45. In addition to these assessments, the Commission observes that the situation faced by that the proposed beneficiary has been occurring despite an *amparo* ruling in her favor. Thus, it is not disproved by the parties that, since November 27, 2014, there has been an *amparo* decision ordering “comprehensive treatment” for her medical condition (see *supra* paras. 6 and 23). Although requests for contempt of court regarding that decision were previously submitted, the Commission observes that the parties indicated that these have been closed (see *supra* paras. 6 and 23). To date, there has only been one contempt of court launched in May 2021 (see *supra* paras. 16 and 23), which is said to be pending resolution by the competent court (see *supra* para. 18).

46. Consequently, in view of the specific characteristics of the instant matter, and in light of the *prima facie* assessment criterion of the precautionary measures mechanism, the Commission concludes that the rights to life, personal integrity, and health of adolescent N.V.E. are at serious risk. In reaching such an assessment, the Commission takes into account her current conditions, as well as the delays reported in the delivery of prescribed medications considered vital to treat her orphan disease, including the medical prescriptions given by medical personnel.

47. Regarding the requirement of *urgency*, the Commission considers that it is also met, inasmuch as, taking into account the diagnosis of the proposed beneficiary, it is necessary to ensure her ongoing medical treatment, with no delay, in order to avoid the worsening of her health and guarantee her quality of life. The IACHR deems it appropriate to recall that surgeries or procedure should only be performed having the prior and informed consent of N.V.E., assuring that she has sufficient information to make any decision. In this sense, it is necessary to immediately carry out the necessary medical assessments, with a multidisciplinary and formed team, in order to fully comply with medical prescriptions, in case this is the adolescent’s will, as well as the possible impacts that are occurring as a result of the orphan disease at present.

48. As regards the requirement of *irreparable harm*, the Commission considers that it is met, given that the possible impact on the rights to life and personal integrity constitutes the maximum situation of irreparability.

IV. BENEFICIARY

49. The Commission declares as beneficiary N.V.E., who is duly identified in this proceeding.

V. DECISION

50. The Commission considers that this matter meets *prima facie* the requirements of seriousness, urgency, and irreparable harm set forth in Article 25 of its Rules of Procedure. Consequently, the Commission requests that Colombia:

- a) adopt the necessary measures to protect the rights to life, personal integrity, and health of N.V.E. In particular, continue to guarantee that she has access to timely medical and psychological treatment, in accordance with the prescriptions and evaluations of competent physicians and under the applicable international standards, including those concerning intersex persons. These measures must be adopted in accordance with the prior, informed, and free consent of the beneficiary; and
- b) consult and agree upon the measures to be adopted with the beneficiary’s representation and the beneficiary, and if applicable, her father, mother, or guardian, considering her age.

51. The Commission requests that the State of Colombia kindly inform the Commission, within a period of 15 days as of the date of this communication, on the adoption of the precautionary measures that have been agreed upon and to periodically update this information.

52. The Commission stresses that, pursuant to Article 25(8) of the Commission's Rules of Procedure, the granting of precautionary measures and their adoption by the State do not constitute a prejudgment regarding the possible violation of the rights protected in the American Convention and other applicable instruments.

53. The Commission instructs its Executive Secretariat to notify this resolution to the State of Colombia and to the applicant.

54. Approved on December 24, 2021, by Antonia Urrejola Noguera, President; Julisa Mantilla Falcón, First Vice-President; Flávia Piovesan, Second Vice-President; Esmeralda Arosemena de Troitiño; Joel Hernández García; and Edgard Stuardo Ralón Orellana, members of the IACHR.

Tania Reneaum Panszi
Executive Secretary