
**INTER-AMERICAN COMMISSION ON HUMAN RIGHTS
RESOLUTION 4/2021**

Precautionary Measure No. 1286-18
Twenty persons diagnosed with Multiple Sclerosis
regarding Venezuela
January 7, 2021
(Extension)
Original: Spanish

I. INTRODUCTION

1. Between 2018 and 2020, the Inter-American Commission on Human Rights (“the Inter-American Commission,” “the Commission” or “the IACHR”) received requests for precautionary measures filed by the organization Defiende Venezuela (“the applicants”) requesting that the Commission require that the Bolivarian Republic of Venezuela (“Venezuela” or “the State”) protect the rights of specific duly identified persons suffering from multiple sclerosis (“the persons proposed as beneficiaries” or “the proposed beneficiaries”). According to the applicants, the proposed beneficiaries are at risk due to the lack of adequate medical treatment to address their medical conditions. It was alleged that the Venezuelan Institute of Social Security (IVSS, by its Spanish acronym) is not delivering the prescribed medications that they should receive to treat their medical conditions.

2. In all the requests that are the subject of this resolution, the Commission requested information from the State in accordance with Article 25 of the Rules of Procedure.

3. Having analyzed the allegations of fact and law provided by the applicants, the Commission considers that the information shows *prima facie* that the identified persons are in a serious and urgent situation, given that their rights to life, personal integrity and health are at risk of irreparable harm. Consequently, in accordance with Article 25 of the IACHR Rules of Procedure, the Commission requests that the State of Venezuela: a) take the necessary measures to protect the life, personal integrity and health of the beneficiaries, by adopting the immediate measures that enable access to adequate medical treatment, including the necessary medications, in accordance with what has been ordered by the corresponding physicians, as well as the diagnoses and tests that allow for the periodic evaluation of their health status, according to the applicable international standards.

II. BACKGROUND

4. On March 29, 2019, the IACHR issued Resolution 18/2019. Through that resolution, the IACHR decided to grant precautionary measures to Inírida Josefina Ramos López, Sara María Olmos Reverón, Miguel Eduardo Perozo González, and Carmen Alicia Márquez de D’Jesus, in Venezuela. The request for precautionary measures filed by the organization Defiende Venezuela alleged that these persons were at risk due to the lack of prescribed medical treatment that be adequate to take care for their medical conditions, being that three persons have “multiple sclerosis,” and one person has “left breast carcinoma with bone metastasis.”

5. Upon analyzing the allegations of fact and law provided by the applicants, the Commission considered that, in principle, Inírida Josefina Ramos López, Sara María Olmos Reverón, Miguel Eduardo Perozo González and Carmen Alicia Márquez de D'Jesus were in a serious and urgent situation, given that their rights to life, personal integrity and health were at risk of irreparable harm. Consequently, in accordance with Article 25 of the IACHR Rules of Procedure, the Commission requested that the State of Venezuela: a) take the necessary measures to protect the life, personal integrity and health of the beneficiaries, by adopting the immediate measures that enable access to adequate medical treatment, including the necessary medications, in accordance with what has been ordered by the corresponding physicians, as well as the diagnoses and tests that allow for the periodic evaluation of their health status, according to the applicable international standards.

6. Following the granting of such precautionary measures, the IACHR has not received a response from the State sufficient to analyze the actions taken to address the situation of the beneficiaries in the exceptional context that the country is going through.

III. SUMMARY OF THE FACTS AND ARGUMENTS PROVIDED BY THE PARTIES

A. Information provided by the applicants

7. The applicants indicated that the treatment for multiple sclerosis depends solely and exclusively on the delivery of drugs by the IVSS belonging to the State of Venezuela, which restricts the possibility of obtaining the drug through a route other than the IVSS supply, as well as refuses to receive humanitarian aid that could provide such medication in the context of scarcity of medicines that the country is going through.

8. The requests indicated that, although there is a High-Cost Pharmacy for the attention of persons diagnosed with several serious diseases whose treatments are expensive, since 2016, the IVSS and the High-Cost Pharmacy excluded persons who represent a minority among the 384 diseases that it covered, suspending the delivery of supplies and ceasing to import immunosuppressants. Moreover, the IVSS purportedly recognized that there are 2,200 persons suffering from Multiple Sclerosis in the country, who have not received medicines in a regular way since 2016. They also indicated that the National Multiple Sclerosis Program, which operated at the Domingo Luciani Hospital of El Llanito, in Caracas, has not been operating since the end of 2017, when most of the neurology specialists at that Hospital were no longer there (many of them had emigrated, as happened with physician Arnoldo Soto, who was director of the Program for several years). On another note, since the beginning of 2018, that service stopped issuing certificates of the condition of Multiple Sclerosis, and no longer delivered medications.

9. The request stressed that the persons proposed as beneficiaries have not been able to update their medical reports due to the high cost of these –on average, in a private clinic the consultation for neurological diseases ranges from 50 to 80 USD, while MRIs cost between 300 and 400 USD–, and due to their condition as persons with disabilities that has made it difficult for them to work. Information on the situation of each of the 20 persons proposed as beneficiaries is presented below.

(1) María Eugenia Monagas de Paris¹

¹ Request filed on October 28, 2018 and registered under PM-1434-18

10. María Eugenia Monagas de Paris (52 years old) suffers from Multiple Sclerosis since 2005. Until 2013, the proposed beneficiary reportedly received the drug Avonex uninterruptedly. However, as of 2014 she has allegedly received it irregularly; even though it should be administered once a week, she has been more than 8 weeks without receiving her treatment. In August 2015, because the drug was purportedly administered so irregularly, it stopped working. In view of this, the IVSS reportedly modified her treatment, administering the drug Natalizumab (Tysabri), which had to be administered every 28 days. During 2016, she allegedly only received 4 doses out of the total 12 doses prescribed, and during 2017 she did not receive any doses. The lack of supply of the drugs is purportedly causing her disease to progress faster.

11. It was indicated that the proposed beneficiary does not live a “normal” life, classifying her illness as chronic. She reportedly cannot get out of bed, having to wait for her husband to pick her up. To go anywhere she must use a walker or a wheelchair. She allegedly feels her leg heavy and her foot is clubfoot, always rigid and pointed. Moreover, she has also seen limitation in her most basic functions such as swallowing or breathing. The proposed beneficiary allegedly sleeps with several pillows. Her food is chopped into very small pieces, given that her breathing capacity is limited as well. The proposed beneficiary is purportedly unable to do her daily tasks because she has lost sensation in her hands and arms. According to the request, the proposed beneficiary has suffered deterioration in her brain and spinal cord, which in turn has had an impact on her mental health. The proposed beneficiary currently leaves her home only when they provide her with a wheelchair, given that walking and dragging her leg causes her such a pain that it makes her cry, spending more time at home sitting or lying down.

12. The applicants referred to the following medical reports:

- Psychiatric report of August 7, 2017: the proposed beneficiary presents with “anxiety symptoms that diminish her cognitive area, along with depressive symptoms that generate hypothymia and insomnia. Such symptoms require lifelong medication and special care under family surveillance.”
- Medical report of April 22, 2019: the proposed beneficiary suffers from “Recurrent Remitting Multiple Sclerosis with an affective disorder, reactive depressive syndrome, has impaired gait, severe motor and sensory disorder, and motor coordination disorder that requires permanent rehabilitation therapies. She presents with pain and limitation at the level of the right hip that generates greater disability. In view of her disease, she has severe musculoskeletal disability with gait impairment, sensory disturbance, does not wander without support and deserves direct accompaniment and care from third parties.” This report indicates that she also requires canes or crutches to walk about 20 meters without rest.
- Medical report of July 9, 2019: It is indicated that “in view of her underlying disease, she presents with severe musculoskeletal disability, with significant disturbances of gait, motor coordination as well as sensory disorders, she does not wander without support and needs direct accompaniment and care by third parties for daily life activities, she has an EDSS (Expanded Disability Status Scale) of 6.5 points (CONSTANT BILATERAL ASSISTANCE, CANES, CRUTCHES, OR BRACES) to walk 20 meters without rest.” The report concludes by recommending permanent rehabilitation and, due to the lack of treatment for multiple sclerosis, the treatment is changed in favor of the drug Fingolimod.
- Medical report of December 4, 2019: a brain MRI concludes that she presents with “hypertensive foci located in deep white matter, periventricular and pericallosal in relation to demyelinating pathology,

classified as MS, in active phase... involutive cortical changes not according to age.”² That is, the proposed beneficiary presents with a deterioration of the central nervous system that is not according to age, in addition to presenting a deterioration in the structure of the spinal cord.

13. The proposed beneficiary used to go to pick up her treatment on a monthly basis as prescribed by the IVSS, but, given that the shortage and non-delivery of the medicine occurred, as well as the lack of information from the IVSS, she filed a claim with the Ombudsman’s Office of the Bolivarian Republic of Venezuela, given the reluctance of the IVSS where she picked up her treatment. On October 19, 2016, the proposed beneficiary filed a complaint via email with the Ombudsman’s Office for the failure to deliver medical treatment, with no response to date. On May 10, 2017, her situation was reiterated in writing to the Ombudsman’s Office of the Mérida state, with no response to date. Similarly, the proposed beneficiary, as president of the Civil Association of Patients with Multiple Sclerosis (ACPEM, by its Spanish acronym), has publicly denounced that 152 vials of interferon beta 1-a donated to the Venezuelan Institute of Social Security disappeared from that body.

14. On June 12, 2019, she reportedly sent an email to the complaint reception system of the Ombudsman’s Office, expressing concern that in 2016 they made a complaint due to the non-delivery of medicines by the IVSS, and as of this date, the Ombudsman’s Office has not acted on her complaint. Lastly, it was indicated that the new treatment prescribed in July 2020 is based on Fingolimod, which is also difficult to obtain.

(2) Larissa Ortigoza Monsalve³

15. The proposed beneficiary (59 years old) has suffered from Multiple Sclerosis since 2010, the year her treatment began. Since December 2016, the IVSS has not provided her with the medical treatment that she was prescribed (medications Tysabri and Fampyra), which has made her mobility difficult, requiring assistance of her family to do her daily activities. The proposed beneficiary allegedly has a severe physical damage caused by the rapid progress of her disease. The applicants refer to three medical reports between 2017 and 2018:

- Medical report of October 27, 2017: the proposed beneficiary suffers from “decreased muscle strength, increased hypoesthesia in her right hand that prevents writing, exacerbated chronic low back pain, dysphagia to eventual solid and liquid foods, flaws in memory, she walks with a walker, given her neurological condition she cannot queue or stand for long.”
- Medical report of July 13, 2018: the proposed beneficiary presents with multiple sclerosis and an EDSS (Expanded Disability Status Scale) of 6.5, which means that the proposed beneficiary needs to lean on two supports and can walk 20 meters without fatigue. In addition, that report states that the proposed beneficiary has had an “outbreak February 2018 (myelitis) managed with Solumedrol. Decreased muscle strength and sensation from her knee down. Loss of fine motor skills. Dysphagia to eventual solid and liquid foods. Memory with flaws. Exacerbation of posture instability, increased spasticity, asthenia and adynamia. In February 2018, she presented with a burning sensation in her lower limbs and instability when walking. She received 1 g of Solumedrol in March 2018. Lesions in D3-D4. She started with Rebif, not being tolerant. Increased myalgia and fatigue. Irritation after Copaxone. Choking sensations.” Furthermore, it is indicated as follows: “Patient who is not receiving immunomodulating medication, which is causing deterioration in her physical and intellectual

² The cervical magnetic resonance revealed that: “concentric protrusion of the C3-C4 and C4-C5 disc, posterior central protrusion C5-C6, hyperintensity in the spinal cord in relation to demyelinating pathology in active phase.”

³ Request filed on October 28, 2020 and registered under PM-1433-18

capacity. Given her neurological condition, she cannot queue, cannot stand, or expose herself to the sun. It is suggested that the relevant authorities provide all possible support.”

- Medical report of October 26, 2018: the proposed beneficiary presents with “generalized paresthesias, optic neuritis, demyelinating plaques, impaired visual and auditory evoked potentials. Lemtrada (alemtuzumab) 12 mg (8 vials) is prescribed.”
- Neurological report of February 19, 2019: the neurological examination reveals motor impairments, pain in the dorsal region that motivates the use of a wheelchair, paraparesis and spasticity.
- Medical report of November 15, 2019: a brain MRI indicates the presence of “hypertensive foci in periventricular white matter centrum semiovale pericallosal, demyelinating disorder.”

16. The proposed beneficiary moves inside her home in walkers, but when going out, she requires the use of wheelchairs, since she has severe pain in her legs. In addition, she reportedly has chronic low back pain, and her episodes of memory loss are more frequent. Given the disability of the proposed beneficiary, she cannot work. The only financial resources available for her are those of her disability pension, which are purportedly insufficient to pay for the medical examinations essential to take care for her disease.

17. Given the non-delivery of the drug Tysabri, which is reportedly the appropriate medication to treat her sclerosis, Lemtrada was reportedly prescribed. However, the applicants also indicated that the IVSS is not delivering the latter drug either. The proposed beneficiary is allegedly using palliative drugs when she presents with outbreaks of the disease, receiving the drug Solumedrol (Methylprednisolone).⁴ However, while treatment with this drug purportedly helps her to withstand the symptoms of multiple sclerosis, it is reportedly not the main drug because only relieves pain, and it is not the ideal one because it causes osteoporosis as a side effect.

18. The proposed beneficiary used to go to pick up her treatment every month as prescribed by the IVSS but given that the shortage and non-delivery of the medicine occurred, as well as the lack of information from the IVSS, she filed a claim with the Ombudsman’s Office of the Bolivarian Republic of Venezuela. On October 19, 2016, the proposed beneficiary filed a complaint via email with the Ombudsman’s Office for the failure to deliver medical treatment, with no response to date. On February 20, 2018, the proposed beneficiary sued the IVSS before the First Court of Administrative Litigation. On May 8, 2018, a request was made to expand and clarify the claim, and no response was given within the period established by law, which corresponded to 3 days after the claim was filed. On April 9, 2019, the claim was declared inadmissible, after one year and two months, because the Court considered that the proposed beneficiary did not file a request for the medication directly to the IVSS. However, at the time, the proposed beneficiary explained to the Court that she did not go directly to the IVSS, but instead filed her complaint to the Ombudsman’s Office, because her health condition prevented her from moving. In this regard, the applicants indicated that the medical reports showing her physical deterioration were submitted to the Court, which made it difficult for them to file a request with the IVSS.

19. On June 12, 2019, she reportedly sent an email to the complaint reception system of the Ombudsman’s Office, expressing her concern that in 2016 they made a complaint due to the non-delivery of medicines by the IVSS, and as of this date, the Ombudsman’s Office has not acted on her complaint.

⁴ This steroid medication purportedly works to treat people with low levels of corticosteroids by replacing the steroids that the body naturally produces during a normal functioning. It also works in treating other conditions by reducing inflammation.

(3) *Gina Vittoria Massimo Alcalde*⁵

20. The proposed beneficiary (53 years old) has suffered from Multiple Sclerosis since 2015, the year she reportedly started her treatment. The proposed beneficiary was allegedly prescribed the drug Natalizumab (Tysabri) in doses of 300 mg, which should be supplied monthly for life. She purportedly received this treatment on December 17, 2015, and the second dose, on January 22, 2016. As a result of this treatment, the proposed beneficiary has been reportedly able to get up from her wheelchair and begin to use crutches, which is why the supply of the drug Fampyra in doses of 10 mg is additionally recommended to improve her movement. However, she only received 5 doses of Natalizumab at the time, having stopped receiving it since October 2016.

21. Given her health condition, the proposed beneficiary is not working and does not have a disability pension either. She reportedly also suffers from incontinence, arterial hypertension (for which she should receive the drug Olmesartan in a dose of 40 mg) and she should take for life Levothyroxine (Euthyrox 150 mcg), because not doing so could further compromise her health given the absence of thyroid. In turn, the lack of treatment purportedly caused that the proposed beneficiary depends on her family members to carry out her daily activities. The state of the proposed beneficiary is reportedly delicate. According to medical reports, she has a severe physical damage, which has purportedly caused a rapid progress of her illness, limiting and disabling the proposed beneficiary.

22. According to the medical report of January 23, 2019, the proposed beneficiary presents with:

“Difficulty walking and standing for more than 1 minute, hyper-reflexive, clonus in her lower limbs, bilateral Babinski, ataxia, signs of depression, sadness and anxiety. (...) Current condition: the general weakness continues, this year she has had two major recurrences, she is currently unable to walk on crutches or canes, walks in a WHEELCHAIR, WITH A DISABILITY GREATER THAN 70%, she has not received treatment since October 2016, she should continue permanently and consistently in treatment with Natalizumab to prevent that her disability progresses. The patient is currently in a wheelchair and depends on a third party, a relative who accompanies her to medical consultations. It is essential for her to receive treatment as soon as possible since she had two exacerbations in less than two months, which weakens her every day and reduces her quality of life.”

23. The medical report of July 9, 2019 indicates the following regarding the proposed beneficiary:

“Current condition: the general weakness continues, this year she has had three major recurrences (outbreaks), she has not received treatment since October 2016, she only moves with support to go to the bathroom and for personal hygiene, the rest of the time she must use a wheelchair, she cannot stay for long in contaminated areas or areas with a large influx of people (such as lockers, banks, offices, etc.) because she is an immunosuppressed patient. Given her history of thyroidectomy and hysterectomy, it is difficult to control her crisis episodes with steroids, she urgently requires specific treatment for multiple sclerosis to stop the progression of the disease and the increase in disability. She has had other complications such as recurrent urinary tract infections, due to neurogenic bladder, because of her multiple sclerosis, in addition to endocrine and metabolic alterations due to the use of steroids, which she cannot stop taking as long as she does not receive the specific treatment to treat her condition.”

⁵ Request filed on November 1, 2018 and registered under PM-1438-18

24. The health condition of the proposed beneficiary has allegedly worsened, to the extent that she moves around only in wheelchair. Upon standing up, after a few minutes, she reportedly feels severe pain in her legs and an intense “tingling” in both feet. Given that the proposed beneficiary spends more time in a wheelchair than standing, she currently goes to rehabilitation for the purpose of doing exercises that allow for mobility in her legs.

25. The proposed beneficiary used to go to pick up her treatment on a monthly basis as prescribed by the IVSS but given that the shortage and non-delivery of the medicine occurred, as well as the lack of information from the IVSS, she filed a claim with the Ombudsman’s Office of the Bolivarian Republic of Venezuela, given the reluctance of the IVSS where she picked up her treatment. On October 19, 2016, the proposed beneficiary filed a complaint via email to the Ombudsman of Venezuela denouncing the lack of medical treatment. On June 12, 2019, she reportedly sent an email to the complaint reception system of the Ombudsman’s Office, expressing concern that in 2016 they made a complaint due to the non-delivery of medicines by the IVSS, and as of this date the Ombudsman’s Office has not acted on her complaint.

(4) Beatriz Aurora Moratinos Oronoz⁶

26. The proposed beneficiary (55 years old) was diagnosed with Multiple Sclerosis since 1995, the date on which she started treatment with interferon beta-1a (Rebif) three times a week. Subsequently, the medication was changed to Tysabri (300 mg every 4 weeks) and as this medication was not available, Solumedrol was prescribed. After 4 years of treatment, the drug Tysabri purportedly started to become scarce in the country, therefore since January 2017 the IVSS does not provide the drug.

27. In view of this situation, basic mobility activities are extremely difficult, hence she requires the assistance of her family. According to the medical certificate dated February 8, 2017, the proposed beneficiary cannot receive Gilenya because of bradycardia, and she cannot receive interferon beta (Avonex) because of intolerance. On January 18, 2019, she filed a complaint with the IVSS, without indicating the response obtained.

28. On October 22, 2020, it was reported that she continues without receiving medical treatment. Only palliative medications have been administered; hence walking is currently very tiring, causing a serious mobility problem. Added to this, she indicates that she has headaches, dizziness, difficulty going to the bathroom, significant fatigue and leg cramps. Regarding medical tests, she emphasized that in 2019, an MRI was performed in which two “pontine infratentorial lesions” were identified, but that due to high costs, she has not been able to update her medical tests. She added that, although another treatment with Rituximab has been indicated, she has not been able to obtain it. Lastly, she stressed that the National Multiple Sclerosis Program, which operated at the “Domingo Luciani” Hospital in El Llanito, in the Caracas Metropolitan Area, has not been operating since the end of 2017, a situation that she has reported to the IVSS and the Ombudsman’s Office on January 18, 2019 and October 21, 2020, without receiving a response to date.

(5) Tatiana Pérez De Chaparro⁷

29. The proposed beneficiary (46 years old) was diagnosed with Multiple Sclerosis in 2005 and received treatment with interferon beta-1a provided by the National Sclerosis Program for 13 years. In

⁶ Request filed on October 22, 2019 and registered under PM-988-19

⁷ Request filed on October 22, 2019 and registered under PM-990-19

2012, she was diagnosed with a neurological musculoskeletal disability, which prevents her from working, completely and permanently. In 2014, the proposed beneficiary presented with kidney failure, so it was decided to change to the drug Natalizumab, but the progressive nature of her disease forced her to return to treatment with Betaferon. She does not receive the later since October 2018, which has caused damage to her body, deep deterioration in her quality of life and disturbances to the family group.

30. She allegedly needs a wheelchair to get around given her quadriplegia. She is purportedly dependent on third parties for her daily activities and treatment with Sertraline was indicated for symptoms of depression. In January 2019, the proposed beneficiary filed a complaint with the Ombudsman's Office, without receiving a response.

31. In October 2020, it was reported that the proposed beneficiary continues without receiving medical treatment. Currently, she allegedly can no longer walk. She has severe memory problems, retinal detachment in her left eye, and her generalized disability makes her require help to bathe, dress, brush, eat, among other activities. Furthermore, she presents with difficulties when speaking and her breathing has been quite affected, suffocating at times. As palliative treatment, the proposed beneficiary has been treated with the drugs carbamazepine and gabapentin, which she has sometimes received through donations. However, she does not have the resources to obtain medications or update her medical tests, due to their cost. It was also stressed that the National Multiple Sclerosis Program, which operated at the "Domingo Luciani" Hospital in El Llanito, in the Caracas Metropolitan Area, has not been operating since the end of 2017.

(6) Crismary Johana Reyes Méndez⁸

32. The proposed beneficiary (32 years old) was diagnosed with Multiple Sclerosis in 2016 and 2018. The symptoms (outbreaks, lack of balance and speech difficulties) have reportedly become stronger and in the absence of the drug interferon beta 1a (Avonex) they purportedly prescribed "Premizona" but due to its side effects the physician reportedly ordered to decrease the dose. In November 2018, the proposed beneficiary requested to IVSS treatment for her disease, receiving the answer that the drug had not been available for more than two years, which has forced her to obtain it privately and at high costs.

33. In October 2018, she was prescribed Tysabri monthly, and in December, due to the decrease in visual acuity, intravenous ocrelizumab was prescribed every six months. The lack of medications has allegedly caused difficulty to do simple activities such as walking, reason why the IVSS is in the process of declaring her totally and permanently incapacitated to work. Although the proposed beneficiary filed a complaint with the IVSS in February 2019, she received no response.

34. On October 6, 2020, it was reported that the proposed beneficiary continues without receiving her medical treatment. She currently affirms that walking causes her a lot of fatigue, she presents with memory problems, speech difficulties, recurrent facial paralysis, "tingling" in her hands and loss of sensation in her extremities, especially in her right foot, having to drag it when walking. The last serious outbreak occurred in August 2020, and she was given the drugs Solumedrol and gabapentin as treatment. She affirmed that she obtains palliative treatment mainly through donations because they have such high costs that she cannot acquire it and that she does not have recent tests due to the same reason and due her condition as a person with a disability that has made it difficult for her to work, so she does not have an income and depends on her relatives. The representatives reported that the National Multiple

⁸ Request filed on October 22, 2019 and registered under PM-991-19

Sclerosis Program, which operated at the “Domingo Luciani” Hospital in El Llanito, in the Caracas Metropolitan Area, has not been operating since the end of 2017. The proposed beneficiary reported her situation to the Administrative Office of the IVSS in Maracaibo on October 6, 2020.

(7) Nieves Yelitza Seijas Pelayo⁹

35. The proposed beneficiary (35 years old) was diagnosed with Multiple Sclerosis since 2014, a disease treated with the drug interferon beta-1a, according to studies conducted in October 2017. Since 2017, she purportedly stopped receiving the prescribed medication hence she had to switch to Solumedrol, a medicine that is not only scarce but whose effects are allegedly not the same as those obtained with interferon. The proposed beneficiary currently presents with hypoesthesia in her face, hands and feet, and her last dose of steroids reportedly occurred on October 26, 2018.

36. On October 5, 2020, it was reported that the proposed beneficiary has not received treatment and only palliative drugs obtained through donations are applied. Her situation of disability has allegedly increased. Walking is very tiring, due to a deficiency in her left leg. She purportedly suffers from dizziness and fainting, along with serious sequelae in her hands to the extent that she makes involuntary moves. She also presents with recurrent facial paralysis, numbness in both upper limbs predominantly on her left side, and difficulties in her vision. In 2019, the proposed beneficiary presented with a sensation of cramps in the upper limbs, heat intolerance, significant fatigue, and urinary incontinence. Ultimately, they indicated that the proposed beneficiary does not have updated medical reports, due to their cost and the condition of a person with a disability. On February 13, 2019, she filed a complaint with the IVSS for the lack of treatment.

(8) Rita Mayela García Peña¹⁰

37. The proposed beneficiary (43 years old) was diagnosed with multiple sclerosis in 2005. She received the drug Rebif as treatment once a week without interruption until 2016, when the IVSS stopped supplying it. Her state of health has purportedly deteriorated, rendering her unable to work, which is why she cannot look after herself and does not have the resources to obtain treatment. On January 14, 2019, a complaint was filed with the Ombudsman’s Office of the Zulia state.

38. As of October 2, 2020, the proposed beneficiary continues without receiving adequate and effective medical treatment for her disease. It was reported that in May 2019 the proposed beneficiary suffered an outbreak of new symptoms and since then she has felt recurrent pain and tingling in her joints, both in her right hand and in her spine, which make mobility difficult for her. To reduce and control these pains, the proposed beneficiary self-medicates by ingesting Ibuprofen and Neurontin. The latter’s active ingredient is gabapentin, which is used to control peripheral neuropathic pain.

39. Similarly, it was indicated that no response was received to the complaint filed in January 2019 with the Ombudsman’s Office of Zulia state. On September 25, 2020, the proposed beneficiary presented the situation of lack of medicine to the high-cost medicine pharmacy, but the person in charge of that place refused to receive it. They specified that the National Program for Patients with Multiple Sclerosis of the IVSS, which authorized the High-Cost Pharmacies of that Institute to provide treatments for this disease, is not working approximately since 2016-2017.

⁹ Request filed on October 22, 2019 and registered under PM-993-19

¹⁰ Request filed on October 22, 2019 and registered under PM-996-19

(9) *Sally Gordon De Madrid*¹¹

40. The proposed beneficiary was diagnosed with Multiple Sclerosis, starting treatment with interferon beta-1a (Rebif). In May 2014, the treatment was changed to Gilenya or fingolimod, a drug that is purportedly not included in the list of drugs delivered by the IVSS and whose incorporation is allegedly pending. The proposed beneficiary has reportedly had to use her personal insurance to buy the drug through a foundation, starting treatment in April 2015 until January 2017, when the drug was definitely in short supply. Ms. Gordon has allegedly resorted to donations from bodies of the national public power and the treating physician, given the shortage of Gilenya, purportedly chose to supply her with Copaxone, which reportedly did not improve or prevent the deterioration of the patient.¹²

41. Ms. Gordon purportedly presents with difficulty walking, deterioration of her mental functions, weight loss, having reached 42 kg, which allegedly means a severe physical impairment. In January 2019, the son of the proposed beneficiary filed a complaint about the lack of the drug with the director of the IVSS hospital in Barquisimeto and on September 20, 2019, he sent a complaint to the IVSS of Lara state, receiving a response stating that there are no medications.

42. On November 11, 2020, it was reported that the proposed beneficiary shows deterioration due to the progress of the symptoms of the disease, therefore her condition is irreversible, the pain is more continuous and does not disappear completely despite administering palliatives such as Solumedrol. She reportedly walks with difficulty and most of the time using a walker. When she needs to leave her house, she requires a wheelchair, which is not easy to come by. Lastly, the applicants stressed that the National Multiple Sclerosis Program, which operated at the “Domingo Luciani” Hospital in El Llanito, in the Caracas Metropolitan Area, has not been operating since the end of 2017.

(10) *Esther Judith Montero Larios*¹³

43. The proposed beneficiary (43 years old) had her first symptoms of the disease in 2007, temporarily disabling her. In 2009, she was diagnosed and in February 2011 she began to be medicated with intramuscular interferon beta-1a, recovering her lost mobility. Since March 2017, she purportedly started receiving this drug irregularly until it was no longer provided. She currently self-medicates with primrose oil or primula, a natural medicine that is reportedly provided by friends and family bringing it from Colombia. The natural treatment has allegedly prevented the proposed beneficiary from relapsing into the immobility of her limbs, but she is prevented from running or jumping, in addition to presenting constant exhaustion. She has been suspended from her job since August 2018 and is currently processing her incapacity for work through the IVSS. The drugs that the proposed beneficiary purportedly lacks are Tysabri and Fampyra and from December 2016 to 2019 she reportedly did not have access to them.

44. A medical report from July 2018 indicates that the proposed beneficiary “began treatment with weekly interferon with a good response until March 2017 when the social security stopped providing it.” In a request filed with the Ombudsperson on February 4, 2019, it was stated that the medication she

¹¹ Request filed on October 28, 2019 and registered under PM-1013-19

¹² Medical report dated October 21, 2016 indicates that the patient suffers from “*Episodes of weakness in his lower limbs, weight loss, increased injury load in the cervical, given her neurological condition she cannot queue or stand for a long time*” and that she does not have the resources to maintain her treatment with the drug Gilenya or fingolimod.

¹³ Request filed on October 28, 2019 and registered under PM-1018-19

requires is Avonex and that she has not received it since 2017. On October 2, 2020, it was reported that her health situation is delicate, because she is not receiving any adequate and effective medical treatment for her disease. The proposed beneficiary cannot walk on her own for more than twenty minutes because she becomes exhausted and begins to feel pain and tingling in her right arm and leg.

45. The proposed beneficiary was checked in 2018 and 2019 by specialists in neurology and radiology, but at present it is impossible to pay for new medical exams due to the COVID-19 pandemic as well as to the situation in the country. Regarding self-medication with primrose oil or primula, they emphasize that the proposed beneficiary has not undergone any specialized neurological assessment or test to determine the consequences of such self-medication, and the closure of borders has prevented access to that medication from Colombia.

46. To date, the proposed beneficiary has not received a response from the Ombudsman's Office. The lack of resources of the proposed beneficiary has prevented her from traveling to bring her situation to the attention of the IVSS. Lastly, they specified that the National Program for Patients with Multiple Sclerosis of the IVSS, which authorized the High-Cost Pharmacies of that Institute to provide treatments for this disease, is not working since 2016-2017.

(11) Roel Díaz Velasco¹⁴

47. The proposed beneficiary (49 years old) was hospitalized from November 13 to 22, 1996 as he felt his left arm suddenly lose strength. At that time, he was diagnosed with Multiple Sclerosis and was treated with the drug Solumedrol. At the beginning of 1997, he was hospitalized again due to loss of sensation in his lower limbs, his back and right arm. Furthermore, he began to receive medical treatment and medications from the Venezuelan Institute of Social Security (IVSS).

48. The request indicated that, for several years, the proposed beneficiary kept his symptoms of the disease under control to some extent. However, in 2009, new symptoms appeared, in particular, visual loss in his left eye, cervical lordosis and desiccation of the nuclei of his intervertebral discs. In this regard, the proposed beneficiary was prescribed treatment with the drug Rebif, through injections three times a week indefinitely. That same year, the proposed beneficiary was included in the IVSS National Multiple Sclerosis Program.

49. The applicants reported that 2010 was a particularly difficult year for the proposed beneficiary as he did not have any improvement with the supply of Rebif. Thus, new symptoms associated with Multiple Sclerosis emerged such as gait ataxia, disability scale of 5 to 6, exacerbation of spasticity and cognitive deterioration. Subsequently, in 2013, the proposed beneficiary was hospitalized as a result of an outbreak of the disease and was prescribed a change of treatment from the drug Rebif to Natalizumab (Tysabri), in doses of 300 mg. On November 19, 2013, the National Council for Persons with Disabilities (CONAPDIS, by its Spanish acronym) certified that the proposed beneficiary has "severe musculoskeletal disability and severe neurological disability."

50. In 2014, the proposed beneficiary began to use a wheelchair permanently due to the intensification of his symptoms, such as spasticity, loss of sensation in upper and lower limbs, and difficulty in controlling his trunk. On June 10, 2014, the IVSS declared the residual disability (67%) of the

¹⁴ Request filed on July 13, 2020 and registered under PM-663-20

proposed beneficiary due to Multiple Sclerosis and bleeding from his left eye. Then, in October 2014, he was hospitalized again for an outbreak and was successfully treated with the drug Natalizumab (Tysabri).

51. From November 18 to 25, 2016, the proposed beneficiary was hospitalized with symptoms of lower limb paresthesia, truncal ataxia, and generalized nystagmus, and was treated with the palliative drug Solumedrol. In October 2017, the proposed beneficiary stopped receiving the drug Natalizumab (Tysabri) from the IVSS through the Pharmacy Service of the Domingo Luciani Hospital. Thus, on March 14, 2018, the proposed beneficiary had a brief outbreak that was treated in a timely manner. The request indicated that this was the last time the proposed beneficiary received Natalizumab (Tysabri).

52. The request stated that body paralysis, paresthesia (“tingling” and burning in the legs), nystagmus and loss of sensation in his extremities are more recurrent due to lack of treatment. In addition, deterioration in his brain’s matter and vertebrae, and the appearance of lacunar foci in the spinal cord have been accentuated since 2016. The proposed beneficiary moves in a wheelchair both inside and outside his house, and spasticity makes it difficult for him to eat. Given the lack of treatment, the proposed beneficiary was given palliatives such as Solumedrol –treatment that is also difficult to obtain due to its high cost–, and motor problems were treated with rehabilitation.

53. In view of the above and given the repeated omissions of information and lack of response by the IVSS that operated at the Domingo Luciani Hospital, on February 1, 2019, the proposed beneficiary filed a complaint with the Ombudsman’s Office of the Metropolitan Area of Caracas, informing that he does not receive the necessary treatment for the condition that affects him and that this harms his right to health because the lack of treatment has damaged his body. In the absence of a response from that body, on June 18, 2020, the proposed beneficiary filed a second complaint with the Ombudsman’s Office.

(12) Nepmari Zambrano Noguera¹⁵

54. The proposed beneficiary (42 years old) began to experience symptoms of Multiple Sclerosis in 2001, when she was only 17 years old, including tingling in her waist and leg (paresthesias), and muscle weakness in her right leg. On November 15, 2001, an MRI report indicated that the proposed beneficiary had degenerative demyelinating lesions in the upper spinal cord, as well as medial dorsal degenerative disc disease. Subsequently, at the beginning of 2002, she was diagnosed with Multiple Sclerosis, was included in the National Multiple Sclerosis Program of the IVSS and was prescribed treatment with the drug Betaferon. Moreover, CONAPDIS certified that the proposed beneficiary presents with “moderate musculoskeletal disability, mild visual disability and mild sensitivity.”

55. The request indicated that the proposed beneficiary traveled monthly from Ciudad Bolívar to the Domingo Luciani Hospital in Caracas to receive the drug Betaferon, but that since July 2016 she has not received it. This resulted in the reappearance and worsening of Multiple Sclerosis symptoms, especially those associated with difficulty walking, given that with the drug the proposed beneficiary could walk with a walker but without it she requires a wheelchair.

56. Subsequently, in 2018, the proposed beneficiary was diagnosed with breast cancer. The request reported that, although she successfully underwent partial mastectomy on June 5, 2018, which removed the infiltrating ductal carcinoma, part of the pharmacological treatment was not performed properly. In this regard, the drugs Doxorubicin (8 vials of 50 mg), Cyclophosphamide (4 vials of 1 g) and Paclitaxel (12

¹⁵ Request filed on July 15, 2020 and registered under PM-676-20

vials of 150 mg) were prescribed to the proposed beneficiary, but they were only administered a couple of times in July and August 2018 because they were already in short supply in the country at that time.

57. In August 2019, several physicians issued orders to perform a computed tomography (CT) scan of thorax, abdomen, and pelvis as well as a breast ultrasound, which were urgently required to accurately determine the stage of the cancer and a possible metastasis. However, the request sustained that, to date, conducting these tests has not been possible because the public hospitals in the city of Bolívar where the proposed beneficiary lives have severe flaws in CT services, therefore she would have to travel to Caracas –located 590 kilometers away– to perform them. Subsequently, on April 16, 2020, brain, cervical and lumbar MRIs, as well as CT of thorax, abdomen and pelvis were ordered to adequately evaluate the current state of health of the proposed beneficiary. However, to the date, these have not been performed either.

58. The request stressed that the lack of treatment and medications is seriously affecting the health status of the proposed beneficiary, including that she is suffering from painful paraparesis when walking, painful holocranial disease and sleep disorder, conditions that are being treated only with palliative medications such as Solumedrol and Diclofenac.

59. In view of the above, and given that the IVSS has denied healthcare provision, on June 25, 2020, the proposed beneficiary filed a complaint with the Ombudsman’s Office of the Bolivarian Republic of Venezuela informing that she does not receive the prescribed treatment for the cancer and Multiple Sclerosis.

(13) Johnny Ceccato Castellanos¹⁶

60. The proposed beneficiary (40 years old) began to present with symptoms of Multiple Sclerosis in 2002. However, he was not diagnosed until October 15, 2007 after suffering episodes of intermittent involuntary movements in his lower limbs. That same year, he was included in the National Multiple Sclerosis Program of the IVSS and was prescribed treatment with the drug Avonex, in doses of 300 mg in the form of intramuscular vials once a week.

61. The request indicated that he was treated with this drug for about 5 years, but as of June 2016, he stopped receiving it because it was “not available in the country.” In view of the shortage of Avonex, in March 2018, the possibility of prescribing other medications, such as Natalizumab (Tysabri) or Fingolimod, was assessed. However, this was not possible because these medications were also in short supply in the country at that moment.

62. In 2017, new symptoms appeared, such as heaviness in his left leg, difficulty walking, fatigue, asthenia and adynamia, frequent forgetfulness, difficulty falling asleep, reactive depression, irritability and anxiety. The request stated that, in the absence of medical treatment from 2017 to present, the proposed beneficiary’s nervous system has deteriorated ostensibly, leading to leukoencephalopathy as well as to a sensory motor disorder in the right half of his body and weakness in his lower left limb. He allegedly can walk with walkers, but he can no longer leave his house because walking is very tiring, and speaking is difficult. Similarly, the spasticity reportedly makes it difficult for him to eat and he has lost 40 kilograms. He is purportedly having to resort to a merely palliative treatment, which is currently difficult to achieve given that it is expensive and can only be obtained through donations from individuals.

¹⁶ Request filed on July 15, 2020 and registered under PM-677-20

63. In view of the above and given the repeated omissions of information and lack of response by the IVSS that operated at the Domingo Luciani Hospital, the proposed beneficiary filed a complaint with the Ombudsman's Office of the Metropolitan Area of Caracas, informing that he is not receiving the necessary treatment from the IVSS. In September of the same year, the proposed beneficiary went to the premises of the Ombudsman's Office in order to know the status of his complaint. There he was informed that the Ombudsman's Office "can only make requests to other institutions and does not have the capacity to oblige them." In the absence of a response from that body, on June 18, 2020, the proposed beneficiary filed a second complaint with it.

(14) Román Tovar Zambrano¹⁷

64. The proposed beneficiary (41 years old) had an episode in December 2013 while driving his car in which he was unable to coordinate his movements, causing a non-fatal accident. In the following months, he developed facial paralysis, "tingling," loss of sensation in the extremities that occurred for periods of 5 to 6 hours, cloudy vision for specific periods of time, some difficulty speaking and abrupt loss of approximately 20 kilograms. The proposed beneficiary was diagnosed with Multiple Sclerosis in June 2014. In March 2015, he was enrolled in the National Multiple Sclerosis Program of the IVSS and was prescribed treatment with Avonex, in doses of 300 mg.

65. The request emphasized that Multiple Sclerosis has been particularly aggressive in the case of the proposed beneficiary, as he has suffered deterioration at the brain's matter level, lacunar foci in the nervous system, dorsal spondylosis and multiple degenerative disc disease. He began receiving treatment with Avonex in March 2015 and until the end of the same year he received the medicine uninterruptedly, but in April 2016, its supply allegedly stopped completely. Instead, a substitute treatment with the drug Pregabalin was indicated, but this drug is reportedly also scarce in the country.

66. The request noted that the proposed beneficiary had an outbreak in September 2019. At that time, he went to the Venezuelan Red Cross where he was treated urgently and was applied Methylprednisolone to alleviate the symptoms resulting from the outbreak.

67. The proposed beneficiary indicated that the lack of treatment for Multiple Sclerosis harms his daily life, stating that he presents with recurrent facial paralysis and "tingling," and that the loss of sensation in the extremities is more recurrent due to the lack of treatment. Furthermore, deterioration at the brain's matter level –specifically in his corpus callosum, brain stem and cerebellar peduncles– and the appearance of lacunar foci in his nervous system, dorsal spondylosis and multiple degenerative disc disease have allegedly accentuated. Moreover, he no longer leaves his house because walking is reportedly very tiring –he could walk with walkers–, speaking is difficult and he has some memory problems, such as easily forgetting where he has left things or performing daily activities. He is purportedly having to resort to a merely palliative treatment, which is currently difficult to achieve given that is expensive and can only be obtained through donations from individuals.

68. In view of the above and given the repeated omissions of information and lack of response by the IVSS that operated at the Domingo Luciani Hospital, on October 22, 2019 the proposed beneficiary filed a complaint with the Ombudsman's Office of the Metropolitan Area of Caracas, informing that he is not

¹⁷ Request filed on July 23, 2020 and registered under PM-705-20

receiving the necessary treatment for the condition he suffers from. Given the lack of response from that body, on June 18, 2020, the proposed beneficiary filed a second complaint with the Ombudsman's Office.

(15) Ligia Elejalde Carabali¹⁸

69. The proposed beneficiary (35 years old) has suffered from migraines since she was 12 years old. Starting in March 2007, at the age of 23, the first symptoms of Multiple Sclerosis began, such as paroxysmal vertigo and unexplained fatigue. She was diagnosed with this disease in 2009, was included in the National Multiple Sclerosis Program of the IVSS in 2013, and was prescribed treatment with Avonex, in doses of 300 mg in the form of intramuscular injections once a week. This treatment was provided from 2013 to 2016 by the IVSS that operated at the Domingo Luciani Hospital located in Caracas, therefore the proposed beneficiary, who lived in the state of Mérida, had to travel regularly to the capital to receive it –a trip of 664 kilometers–.

70. The request noted that, although the proposed beneficiary remained having the lesions typical of Multiple Sclerosis at the brain level, the provision of the treatment Avonex prevented the severity of the symptoms. However, as of January 2017, she stopped receiving treatment, which has resulted in the reappearance of some symptoms, such as migraines, paroxysmal vertigo, and chronic fatigue. In the same sense, the physical condition of the proposed beneficiary purportedly shows deterioration and worsening of the symptoms of the disease. She allegedly has difficulty walking, being able to walk only a few meters leaning on canes and taking pauses for minutes. When trying to walk without help, she reportedly has an erratic gait due to paroxysmal vertigo that allegedly makes her lose her balance. Similarly, it is indicated that she presents with “tingling” and a burning sensation on the skin, as well as migraines that are currently more recurrent, and that many times the pain does not completely disappear despite the application of palliatives such as Solumedrol and Prednisone. These palliative measures allegedly do not avoid the motor and balance impairment that affects the proposed beneficiary.

71. In view of the above and given the repeated omissions of information and lack of response by the IVSS that operated at the Domingo Luciani Hospital, on June 18, 2020 the proposed beneficiary filed a complaint with the Ombudsman's Office, informing that she is not receiving the necessary treatment for the condition she suffers from.

(16) Humberto Ávila Henríquez¹⁹

72. The proposed beneficiary (28 years old) was taken urgently to the hospital with severe abdominal pain in October 2008. He was discharged, but in the following months he presented with facial paralysis, “tingling,” sphincter disorders, dizziness, gait disturbance, loss of sensation and strength in the extremities that occurred for periods of 5 to 6 hours, blurred vision and an erratic movement in his eyes called “nystagmus,” that forced him to turn his head to the right to see. Subsequently, in January 2009, he was diagnosed with Multiple Sclerosis, was included in the National Multiple Sclerosis Program of the IVSS and was prescribed treatment with the drug Rebif, at a dose of 44 mg 3 times a week.

73. In 2013, the proposed beneficiary had an outbreak with symptoms of paresthesia and sphincter disorder that was treated with Solumedrol intravenously for 5 days, and recovery was achieved 3 months after applying that treatment. Subsequently, in 2015, he had a new outbreak, which produced weakness

¹⁸ Request filed on July 23, 2020 and registered under PM-706-20

¹⁹ Request filed on July 23, 2020 and registered under PM-707-20

of his left and right lower limbs, involuntary movements of the right upper limb and loss of mobility of the left upper limb.

74. The request indicated that the proposed beneficiary received treatment with Rebif from 2010 to 2015, which significantly reduced his symptoms of Multiple Sclerosis. However, due to his 2015 outbreak, treatment was changed in favor of the drug Natalizumab (Tysabri), 300 mg every 28 days, which was supplied until October 2017, when the proposed beneficiary purportedly stopped receiving it given its scarcity in the country.

75. As a result of the lack of treatment, the proposed beneficiary's health reportedly seriously deteriorated, and he currently has to remain bedridden. Thus, in 2019, the proposed beneficiary suffered two intense outbreaks in the months of March and July, respectively. In the same sense, a medical report dated May 20, 2019 indicates that the proposed beneficiary: "has been diagnosed with Multiple Sclerosis for 19 years, which has progressively compromised his vital capacities. He has received treatment irregularly. Physical examination: enters in wheelchair, conscious, does not emit sounds, responds to stimuli, with facial gestures. Spastic upper and lower limbs, with limited passive activity. No head or trunk control. Lower limbs in flexion with reducible clubfoot. No sphincter control. Train family members in bed and chair positioning. Improve trunk and head control. Help is appreciated to buy disposable diapers, bed underpad, L-Carnitine, folic acid and cerebral oxygenator." The proposed beneficiary is purportedly having to resort to a merely palliative treatment with the medication Salumedrol, which is currently difficult to achieve given that is expensive and can only be obtained through donations from individuals.

76. In view of the above and given the repeated omissions of information and lack of response by the IVSS that operated at the Domingo Luciani Hospital, on October 22, 2019 the proposed beneficiary filed a complaint with the Ombudsman's Office of the Metropolitan Area of Caracas, informing that he is not receiving the necessary treatment for the condition he suffers from. Given the lack of response from that body, on June 18, 2020, the proposed beneficiary filed a second complaint with the Ombudsman's Office.

(17) Eliana Ruiz Garcia²⁰

77. The proposed beneficiary (40 years old) began to have her first symptoms of Multiple Sclerosis in 2013, such as loss of sensation, loss of strength in her arms, blurred vision, and gait disturbance to the point that she constantly lost her balance. However, it was not until 2015 that she was diagnosed with the disease and included in the National Multiple Sclerosis Program of the IVSS. Treatment with the drug Rebif was prescribed, at a dose of 44 mg three times a week, and the drug Fampyra, which helps with the gait of persons with multiple sclerosis. Furthermore, on October 13, 2015, CONAPDIS issued a disability certificate certifying that the proposed beneficiary has a "moderate-degree musculoskeletal disability."

78. The request indicated that the IVSS was supplying the drug Rebif to the proposed beneficiary in a timely manner until February 24, 2017, when she received the last delivery, and the drug Fampyra until April 2018.

79. In that sense, in view of the lack of treatment, the physical condition of the proposed beneficiary reportedly shows deterioration and worsening of the symptoms of the disease. Thus, she purportedly loses her balance easily and only walks with a walker, since the cane is insufficient because she does not

²⁰ Request filed on July 23, 2020 and registered under PM-708-20

have strength in her lower extremities. She allegedly has blurry vision and feels pain. In addition, she reportedly has some memory problems, in relation to which a neurocognitive assessment report prepared in May 2016 indicated that the proposed beneficiary has “compromise of two cognitive domains, selective attention, cognitive flexibility, working memory, verbal fluency and speed of processing, these compromised functions show affectation at the frontal level.” The proposed beneficiary is purportedly having to resort to a merely palliative treatment with the medication Salumedrol, which relieves pain but has not prevented the visual and motor impairment that affects her.

80. In view of the above and given the repeated omissions of information and lack of response by the IVSS that operated at the Domingo Luciani Hospital, on June 18, 2020 the proposed beneficiary filed a complaint with the Ombudsman’s Office, informing that she is not receiving the necessary treatment for the condition she suffers from.

(18) Yakeisy Longa Rivero²¹

81. The proposed beneficiary (21 years old) began to have symptoms of Multiple Sclerosis in 2008 when she was 8 years old, such as paralysis of half of her body, difficulty in grasping objects, loss of balance and blurred vision. In September 2008, she was diagnosed with the disease and was prescribed treatment with interferon beta 1-a, rehabilitation therapy and psychological assessment. The proposed beneficiary was hospitalized from July 6 to July 14, 2009, with new symptoms such as diplopia, associated with the existence of optic neuromyelitis and hemiparesis on the right side of her body, to the point that she dragged her right leg. Subsequently, she was hospitalized in June 2010 and May 2011, when she was prescribed treatment with the drug Betaferon.

82. The request indicated that, once receiving treatment with Betaferon, the proposed beneficiary kept Multiple Sclerosis under control. However, since August 2016, she has had difficulty in obtaining the drug, which resulted in the reappearance of several symptoms. Thus, from September 2 to 13, 2016, the proposed beneficiary was hospitalized due to a new outbreak with symptoms such as paresthesia, headache, and loss of muscle strength in both lower limbs that prevent her from walking as she used to. Given the lack of Betaferon, on that occasion she was treated with the palliative Solumedrol.

83. The request indicated that during 2018 the symptoms of the disease intensified –headaches, diplopia and paralysis of the left side of the body, among others–. Thus, from April 2 to 20 of the same year, she was hospitalized and was only treated with the palliative Solumedrol due to the lack of Betaferon.

84. Given the lack of treatment, the physical condition of the proposed beneficiary purportedly shows deterioration and progress of the symptoms of the disease. In this regard, the request stated that, despite being 21 years old, the proposed beneficiary requires a cane to walk inside her home, because the loss of balance is constant and very exhausting, therefore she does not leave her home either. Similarly, she reportedly has some vision problems, specifically diplopia, associated with the existence of optic neuromyelitis, as well as hemiparesis on the right side of her body, to the extent that she allegedly drags her right leg. The proposed beneficiary is allegedly having to resort to a merely palliative treatment with the medication Salumedrol, which relieves pain but has not prevented the visual and motor impairment that affects her.

²¹ Request filed on July 23, 2020 and registered under PM-709-20

85. In view of the above and given the repeated omissions of information and lack of response by the IVSS that operated at the Domingo Luciani Hospital, on February 1, 2019 the proposed beneficiary filed a complaint with the Ombudsman's Office, informing that she is not receiving the necessary treatment for the condition she suffers from. Given the lack of response from that body, the proposed beneficiary filed a second complaint with the Ombudsman's Office on June 18, 2020.

(19) María Aguila Prato²²

86. The proposed beneficiary (38 years old) was diagnosed with Multiple Sclerosis in January 2016, receiving Solumedrol that allowed her to recover the functions that were compromised such as movement and hearing. She was included in the National Multiple Sclerosis Plan of the IVSS and began to receive the drug Rebif as treatment, which she received constantly until 2017, but after this year and due to the lack of the drug, she relapsed, being hospitalized for a month and developing new lesions that left irreversible sequelae at the motor and sensory level in her upper and lower limbs. The proposed beneficiary allegedly indicated that, by the end of 2017, of five treatments that arrived imported to Venezuela, only 2 were left, so they had to change it to Betaferon. The delivery of the medicine was not made as of February 2018, date from which she has been without treatment and is reportedly resorting to the administration of Solumedrol. However, on November 19, 2018 she allegedly had a new outbreak of the disease, hence she had to be hospitalized. On November 20, 2018, she filed a complaint with the IVSS, without indicating the response obtained.

87. On November 11, 2020, it was reported that the proposed beneficiary finds it difficult to walk, always leaning on a walker, and tends to fall if she tries to walk without assistance. The pains are reportedly more continuous, and at many times they do not disappear completely despite the application of palliatives like Solumedrol. This medication relieves pain, but it has not prevented motor and balance impairment, or the migraines that afflict her. In addition, she receives Prednisone. In 2019, she had two outbreaks, one of them occurred in August, for which Rituximab was prescribed. This drug is a difficult to obtain and very expensive palliative. Since August 2019, the proposed beneficiary has been unable to obtain either Solumedrol or the prescribed Rituximab. An MRI scan performed on the proposed beneficiary in February 2020 indicated that the proposed beneficiary continues to show a deterioration in her central nervous system due to Multiple Sclerosis.

88. Lastly, the applicants indicated that due to the repeated omissions of information and lack of response from the IVSS that operated in the Hospital "Domingo Luciani," the proposed beneficiary chose to go to the Ombudsman's Office, filing a request for treatment on November 6, 2020.

(20) Lourdes Verenzuela Mavares²³

89. The proposed beneficiary (63 years old) was diagnosed with Multiple Sclerosis in 2013, receiving interferon beta-1a (Avonex) weekly and Neurontin. Such drugs have purportedly been provided by the IVSS until November 2016, date since when there are no more supplies. According to the request, the proposed beneficiary has difficulty walking, numbness in her legs, and impairment in the cognitive area that purportedly makes it difficult for her to retain information.

²² Request filed on October 28, 2019 and registered under PM-1017-19

²³ Request filed on October 28, 2019 and registered under PM-1016-19

90. On November 4, 2020, it was reported that the proposed beneficiary currently has fatigue, “memory difficulties” and tingling in her arms and face, being treated with the drug Gabapentin. She had an outbreak of the disease that occurred in early 2019 and since then she allegedly does not have updated medical tests. She went to the neurologist at the Caracas University Hospital of the Central University of Venezuela, where they told her that she should have a brain MRI with contrast, in order to see the lesions in her brain, as well as physiotherapy and rehabilitation. However, she was not able to undergo those procedures because of the cost. On February 6, 2019, the proposed beneficiary filed a complaint with the IVSS for the lack of treatment for her illness.

B. Response from the State

91. Pursuant to Article 25 of the Rules of Procedure, the Commission requested information on all the matters that are the subject of this resolution. On June 11, 2019, information was requested on the situation of Larissa Ortigoza Monsalve; on June 12, 2019, on the situation of María Eugenia Monagas de Paris and Gina Vittoria Massimo Alcalde; on October 7, 2020, on the situation of Nepmari Zambrano Noguera, Johnny Ceccato Castellanos, Román Tovar Zambrano, Ligia Elejalde Carabali, Humberto Ávila Henríquez and Yakeisy Longa Rivero; on October 8, 2020, on the situation of Eliana Ruiz Garcia; on October 14, 2020, on the situation of Esther Judith Montero Larios; on October 23, 2020 on the situation of Roel Díaz Velasco; on October 22, 2020, on the situation of Nieves Yelitza Seijas Pelayo; on October 14, 2020, on the situation of Rita Mayela García Peña; on November 3, 2020, on the situation of Beatriz Aurora Moratinos Oronoz; on December 4, 2020, on the situation of Crismary Johana Reyes Méndez; on December 7, 2020, on the situation of Tatiana Pérez De Chaparro and Sally Gordon De Madrid; and on December 21, 2020, on the situation of María Aguila Prato and Lourdes Verenzuela Mavares.

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

92. Precautionary measures are one of the mechanisms of the Commission for the exercise of its function of overseeing compliance with human rights obligations, as established 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 Rules of Procedure of the Commission. 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.

93. The Inter-American Commission and the Inter-American Court of Human Rights (“the Inter-American Court” or “I/A Court H.R.”) have established repeatedly that precautionary and provisional measures have a dual nature, protective and precautionary. As regards the protective nature, these measures seek to avoid irreparable harm and preserve the exercise of human rights. Regarding their precautionary nature, these measures have the purpose of preserving legal situations while they are being considered by the IACHR. Their precautionary nature aims to safeguard the rights at risk until the request under consideration in the Inter-American System is resolved. The object and purpose are to ensure the integrity and effectiveness of the decision on the merits and, thus, avoid infringement of the rights at issue, a situation that may adversely affect the useful purpose (*effet utile*) of the final decision. In this regard, precautionary or provisional measures allow the State concerned to comply with the final decision and, if necessary, implement the ordered reparations. Regarding the process of decision making and, according to Article 25(2) of the 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
- c. “irreparable harm” refers to injury to rights which, due to their nature, would not be susceptible to reparation, restoration or adequate compensation.

94. Before analyzing the procedural requirements, the Commission clarifies that it is not called upon to determine, through the precautionary measures mechanism, whether there is international responsibility of the State of Venezuela in relation to the alleged facts or to determine violations of the human rights of the persons proposed as beneficiaries. When analyzing the requirements established in Article 25 of the Rules of Procedure, the Commission is only called upon to determine whether there is a serious and urgent situation of irreparable harm to the human rights of the persons proposed as beneficiaries. The facts supporting a request for precautionary measures need not be proven beyond doubt; rather, the purpose of the assessment of the information provided should be to determine *prima facie* if a serious and urgent situation exists.²⁴

95. The Commission initially processed the situation of the twenty persons under new registries when these were filed as new requests for precautionary measures between 2018 and 2020. However, the Commission observes that such requests refer to events that the proposed beneficiaries have been facing since approximately 2014 in Venezuela. Moreover, it is noted that the alleged situations have persisted over time since then to date and focus on the lack of delivery of prescribed medications for the Multiple Sclerosis disease suffered by the persons proposed as beneficiaries and the impacts that this situation reportedly generates on their health. In this sense, the Commission takes into account that up to a certain point such people received medical care from national authorities such as the IVSS, ceasing to receive it from the State in the context of the country in recent years.

96. Taking the above into account, the Commission notes that the alleged facts have a “factual connection” with the precautionary measures granted through Resolution 18/2019 on March 29, 2019, which refer to four persons with Multiple Sclerosis in Venezuela and the impacts on the health that result from the fact that the IVSS is not delivering the medications they have been prescribed. For the Commission, then, there is compliance with the requirement for the extension of such precautionary measures. That is, the “factual connection” with the events that justified the initial adoption of the precautionary measures.²⁵

97. When making this determination, the Commission acknowledges that despite the requests for information made to the State in the framework of the new requests for precautionary measures, the competent national authorities reportedly have knowledge at the domestic level of the situation faced by the twenty persons proposed as beneficiaries since at least 2014, the average year from which the

²⁴ In this regard, for instance, referring to the provisional measures, the Inter-American Court has indicated that a minimum of detail and information is required to *prima facie* assess a situation of extreme seriousness and urgency. I/A Court H.R., *Matter of the children and adolescents deprived of their 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.

²⁵ See in this regard: IACHR, Resolution 10/17, Precautionary Measure No. 393-15 Detainees in “Punta Coco” regarding Panama, March 22, 2017, para. 28; and I/A Court H.R., Fernández Ortega et al. regarding Mexico. Order of Provisional Measures of November 23, 2010, considerandum 19.

competent national authorities progressively began to stop providing prescribed medical treatments. The Commission also notes that the twenty persons proposed as beneficiaries share the same representatives as those four who are already beneficiaries through Resolution 18/2019 of March 29, 2019.

98. The decision to address the situation presented as a request for extension is also coherent with what was indicated by the Inter-American Court when addressing requests for extension regarding Venezuela. In this regard, the Commission observes that, in a resolution to expand provisional measures dated July 8, 2020 in *Matters of certain penitentiary centers, Humberto Prado, and Marianela Sánchez Ortiz and family in Venezuela*, the Inter-American Court considered “a series of facts, some more recent and others from a few years ago, which are presented as a continuity and which, as has been argued, denote a situation of risk within the framework of a particular current context.”²⁶ Like the Inter-American Court, the Commission understands that, in the twenty cases presented, there are facts, some recent and others from years ago, that are presented as a continuity to the present.

99. On another note, according to the case law of the Inter-American Court, the right to health “[...] begins with the duty of regulation, for which it has indicated that States are responsible for permanently regulating the provision of services (both public and private) and the enforcement of national programs related to the achievement of quality service provision[...] General Comment No. 14 of the ESCR Committee on the right to the enjoyment of the highest possible level of health [...] emphasized that the right encompasses timely and appropriate health care, as well as the following essential and interrelated elements of availability, accessibility, acceptability and quality, whose application will depend on the prevailing conditions in each state [...]”²⁷ Regarding the duty of regulation, in light of the information available, in the present mechanism it is not necessary to rule on its scope concerning Venezuela with respect to the provision of medical services or whether it is appropriate for the State to specifically regulate, in its domestic law, the delivery of certain medications to treat Multiple Sclerosis. The above because, in the present matter, the Commission understands that all the prescribed drugs that the proposed beneficiaries have stopped receiving had been previously received and delivered by the State, hence it is not controversial that such drugs were part of the list of drugs that Venezuela had already regulated in its domestic law and that it had been delivering according to the medical assessments by the competent national authorities of the health sector to each person proposed as beneficiary.

100. Having clarified these preliminary issues, the Commission proceeds to analyze compliance with the procedural requirements in accordance with Article 25 of the Rules of Procedure. When analyzing such requirements, the Commission notes that the situation of scarcity and shortage of medications, supplies, material, and medical treatment in Venezuela has been worsening since 2014.²⁸ As assessed by the IACHR in 2017, the situation has reached a critical point because of the serious political, economic and social crisis,²⁹ characterized by, among others, the shortage and shortage of medicines, supplies, material and medical treatment. In addition, this situation has worsened given the prolonged periods of

²⁶I/A Court H.R. Matter of Certain Penitentiary Centers in Venezuela. Humberto Prado. Marianela Sánchez Ortiz and family regarding Venezuela. Provisional Measures. Order of the Inter-American Court of Human Rights of July 4, 2006. Considerandum 22. Available at https://www.corteidh.or.cr/corteidh/docs/medidas/centrospenitenciarios_se_06.pdf

²⁷I/A Court H.R., Case Cuscul Pivaral et al. v. Guatemala. Preliminary objection, merits, reparations and costs. Judgment of August 23, 2018. Series C No. 359, para. 106.

²⁸IACHR. IACHR and its Special Rapporteurship on Economic, Social, Cultural, and Environmental Rights Condemn the Violent Repression in Venezuela and Urge the State to Protect Human Rights in the Current Political, Economic and Social Crisis. March 1, 2019. Available at http://www.oas.org/en/iachr/media_center/PReleases/2019/052.asp

²⁹IACHR, Country report. Democratic Institutionalality, Rule of Law and Human Rights in Venezuela, December 31, 2017, para. 470. Available at: <http://www.oas.org/es/cidh/informes/pdfs/Venezuela2018-es.pdf>; IACHR, IACHR Alerts About Further Weakening of Rule of Law in Venezuela Ahead of New Presidential Mandate, January 9, 2019. Available at https://www.oas.org/en/iachr/media_center/PReleases/2019/005.asp

lack of electricity that has caused the lack of access to services and multiple effects on the rights of Venezuelans.³⁰

101. In preliminary observations in 2020, after the historic *in loco* visit to Venezuela to monitor the human rights situation, the Commission was able to verify the lack of clear, accurate and reliable information on the health situation and the health system, noting that this opacity not only makes groups in a vulnerable situation invisible, but also prevents knowing the magnitude of the crisis and the design of public policies to overcome it.³¹ During its field visit, the Commission compiled testimonial information on the precariousness of health services.³² In this regard, the Commission notes that the facts alleged in the requests that are the subject matter of this resolution are framed in an exceptional context that is decisive for their assessment. Additionally, this context has worsened over time.

102. According to the information available, the twenty proposed beneficiaries suffer from “Multiple Sclerosis.” In this regard, the Commission considers in its assessment that, according to specialized entities, it is an incurable central nervous system disease that can cause disability.³³ Over time, the disease may cause the nerves themselves to deteriorate or become permanently damaged.³⁴ According to the Pan American Health Organization (PAHO), the loss of productivity may be significant.³⁵ Some persons with severe multiple sclerosis may lose the ability to walk without assistance or to walk at all.³⁶ However, some treatments help with recovery, change the course of the disease, and control symptoms.³⁷

103. Taking the above into account, the Commission notes that, according to the available information, the IVSS or the corresponding state hospital have been delivering the prescribed medications for the proposed beneficiaries, who have stopped receiving them in the context of the serious situation that Venezuela is going through. In this sense, it is observed that the twenty persons proposed as beneficiaries have reportedly not received the prescribed medical treatment, on average, for periods of more than 26 months. In some cases, certain persons have purportedly not received treatment since the end of 2016, which is equivalent to approximately more than 50 months. Consequently, some proposed beneficiaries have resorted to palliative medications or alternative treatments, and others have self-medicated with other medications. In this regard, according to the information available, the Commission observes that such treatments are allegedly not the ideal ones to treat the disease or the ones that they had been receiving over time either. In that sense, such treatments have reportedly had consequences on their health, given that they have not mitigated the advance of the disease. In particular, the Commission notes that, although some persons obtained certain medicines on their own, this situation is no longer possible or is more difficult now, given the current context of the COVID-19

³⁰IACHR, IACHR and SRESCER Express Their Concern Over the Lack of Electricity and Drinking Water in Venezuela, Press release No. 77/019 of March 22, 2019. Available at https://www.oas.org/en/iachr/media_center/PReleases/2019/077.asp

³¹IACHR. IACHR Presents Preliminary Observations and Recommendations Following Historic On-Site Visit to Monitor the Human Rights Situation in Venezuela. May 8, 2020. Available at http://www.oas.org/en/iachr/media_center/PReleases/2020/106.asp

³²*Ibid.*

³³MAYO CLINIC, Multiple Sclerosis, Overview. Available at <https://www.mayoclinic.org/diseases-conditions/multiple-sclerosis/symptoms-causes/syc-20350269> See also: PAHO, Neurological Disorders. Challenges for public health, 2006, Available at: http://www1.paho.org/hq/dmdocuments/2008/Trastornos_Neurologicos.pdf It is stated that “there are no curative treatments available.”

³⁴*Ibid.*

³⁵PAHO, Neurological disorders. Challenges for public health, 2006, Available at: http://www1.paho.org/hq/dmdocuments/2008/Trastornos_Neurologicos.pdf

³⁶MAYO CLINIC, Multiple Sclerosis, Overview. Available at <https://www.mayoclinic.org/diseases-conditions/multiple-sclerosis/symptoms-causes/syc-20350269>

³⁷MAYO CLINIC, Multiple Sclerosis, Overview. Available at <https://www.mayoclinic.org/diseases-conditions/multiple-sclerosis/symptoms-causes/syc-20350269>. See also: PAHO, Neurological Disorders. Challenges for public health, 2006, Available at: http://www1.paho.org/hq/dmdocuments/2008/Trastornos_Neurologicos.pdf

pandemic and the closure of borders. The allegations provided by the applicants are consistent with the exceptional context identified by the IACHR.

104. In this line, the Commission also emphasizes that the complex humanitarian situation in Venezuela is even more difficult for persons with pre-existing chronic diseases in the context of the current pandemic, in which States are obliged to ensure equitable distribution and access to health facilities, goods and services without any discrimination, ensuring care for persons with pre-existing diseases that make them especially vulnerable to the virus, such as persons affected by multiple sclerosis.³⁸ As the IACHR and its REDESCA have sustained, given the viral nature of COVID-19 transmission, certain social groups are at greater risk of suffering differentiated impacts and having their rights more easily affected; among them are the persons with certain pathologies and diseases, such as multiple sclerosis, therefor the measures adopted must include actions to prevent contagion and guarantee medical care and treatment, medicines and supplies, avoiding the differentiated impacts of the lack of supplies.³⁹

105. Moreover, the Commission identifies that, given the alleged failure of the IVSS to deliver the prescribed medications, the proposed beneficiaries are reportedly suffering from medical complications, which could be severe and irreversible. For the Commission it does not go unnoticed that, according to the information available, the proposed beneficiaries are not able to update their medical reports or undergo new tests to have a more precise diagnosis of their medical condition because the services of the nearby hospitals are mostly non-operating and they do not have funds necessary to carry them out in private entities. In the same way, the Commission notes that the proposed beneficiaries do not have the option of accessing the medications on their own either, given that the State has reserved for itself most of their importation and delivery in the country. In the case of the persons who were able to have medical reports between 2017 and 2019, the Commission notes that they reveal a progressive advance in the symptoms of Multiple Sclerosis, which allegedly has an especial impact on the nervous system and its motor capacity, which may become irreversible or progress if timely medical treatment is not received.

106. The Commission notes that, according to the information available, the alleged situation of risk is known to the IVSS. This state entity has allegedly stopped providing medications, and repeated requests for the delivery of medications and treatment have been filed with it. Even complaints or requests have been filed before that entity, in view of the lack of response. Furthermore, the information available indicates that the IVSS authorities have not provided information to the proposed beneficiaries and have been reluctant to provide treatment. The Commission further notes that the National Multiple Sclerosis Program, which operated at the Domingo Luciani Hospital in El Llanito, in the Caracas, has not been operating since the end of 2017. In this regard, it is noted that in some cases it was also requested that the Ombudsman's Office interceded to carry out the necessary actions to achieve, within the framework of its powers, the delivery of medications prescribed. In some cases, the proposed beneficiaries even indicated that they do not have the possibility to go to the institutions and make requests, having made use of electronic means.

107. In the case of Larissa Ortigoza Monsalve, the Commission observes that a lawsuit was filed in 2018, and that in April 2019 it was declared inadmissible, requiring that a request be filed with the IVSS. In this regard, it is observed that even if the proposed beneficiary had sought to file the request with the IVSS, it was reported that the National Multiple Sclerosis Program is no longer operating since at least

³⁸IACHR, Resolution 1/2020 Pandemic and Human Rights in the Americas, Rec. 8.

³⁹Cfr. IACHR and OSRESCER. Press Release No. 060/2020: IACHR and OSRESCER Urge States to Guarantee Comprehensive Protection for Human Rights and Public Health during the COVID-19 Pandemic, March 20, 2020.

2017. Notwithstanding the fact that the applicants indicated that the medical reports that revealed the physical deterioration of the proposed beneficiary were submitted to the Judiciary, which made it difficult for them to file a request with the IVSS at the time. The Commission observes that given the context of the pandemic, the Venezuelan judiciary remained closed or with serious restrictions for the processing of complaints,⁴⁰ which is relevant when analyzing the situation of the proposed beneficiaries in case they had sought to file their complaints judicially in the exceptional context the country is going through.

108. Considering the situation within the context of the particular crisis that Venezuela is going through, as well as the domestic actions initiated, the Commission does not identify information that could indicate that the alleged risk faced by the proposed beneficiaries has been effectively addressed by the State. In these circumstances, the Commission regrets the lack of a substantial response on the part of the State, especially in view of the nature of the alleged facts in the current context of the country. Although this does not in itself justify the granting or extension of precautionary measures, it does prevent the Commission from hearing its observations on these requests for precautionary measures. In these conditions, the Commission considers that the State has not provided information regarding the health situation of the persons proposed as beneficiaries, the suitability of the medication they purportedly require or the difficulties in guaranteeing their access, or if they have a suitable alternative treatment. In this sense, there are no sufficient elements to disprove the worrying situation of risk alleged by the applicants.

109. This lack of information is particularly serious for the Commission. Despite having precautionary measures in force in favor of four people with Multiple Sclerosis since 2019, the Commission also does not have information to indicate that the situation in which the precautionary measures are framed has been duly mitigated. In particular, the Commission takes note of the current facts within the particular context of the country, considering that a large part of Venezuela's health centers do not continuously have potable water, electricity, hygiene and prophylaxis supplies, surgical equipment, laboratories for blood transfusion controls, material for sterilizing instruments, vaccines for basic immunizations, diagnostic contrast media, or operational elevators.⁴¹

110. In this regard, taking into account the exceptional situation that the State of Venezuela is going through, and that the health of the proposed beneficiaries is deteriorating due to the lack of medical treatment prescribed for long periods of time, in addition to the seriousness that the diseases they suffer represent and the lack of response from the State, the Commission concludes, from the applicable *prima facie* standard, that the rights to life, personal integrity and health of the persons identified herein are at serious risk. At the time of carrying out this assessment, the Commission takes into account that access to medications is an integral part of the right to health. Moreover, essential medications must be provided to treat diseases that pose a public health risk or to cover those priority needs for people's health in Venezuela.⁴²

⁴⁰SUPREME INJUSTICE, COVID-19 has paralyzed the Venezuelan justice, May 5, 2020. Available at: <https://supremainjusticia.org/2020/05/05/el-covid-19-ha-paralizado-a-la-justicia-venezolana/> ; The TSJ partially reopens the courts after almost seven months closed by the pandemic, October 6, 2020. Available at: <https://supremainjusticia.org/2020/10/06/el-tsj-reabre-parcialmente-los-tribunales-tras-casi-siete-meses-cerrados-por-la-pandemia/>

⁴¹ Cfr. Press Release No. 064/2020, IACHR and its SRESCER Deeply Concerned about the Impact of COVID-19 Pandemic on Venezuela, Call for Safeguards for the Rights of Venezuelans around the Americas, March 29, 2020

⁴² IACHR. IACHR and its Special Rapporteurship on Economic, Social, Cultural, and Environmental Rights Condemn the Violent Repression in Venezuela and Urge the State to Protect Human Rights in the Current Political, Economic and Social Crisis. March 1, 2019. Available at http://www.oas.org/en/iachr/media_center/PReleases/2019/052.asp

111. Regarding the urgency requirement, the Commission considers that it has been met, in view of the alleged deterioration in the health of the proposed beneficiaries and also considering that the State itself has reportedly stopped delivering the drugs for long periods of time, and these have not been delivered to date despite various actions undertaken by the proposed beneficiaries. Even when they were undertaken, it has been reported that the National Multiple Sclerosis Program has not been operating for approximately 3 years, which makes it necessary to adopt additional measures as soon as possible. Given the lack of response from the State, the Commission does not have actual information sufficient to assess the actions that are being taken to address the alleged risk faced by the proposed beneficiaries in light of the exceptional context that Venezuela is going through.

112. As it pertains to the requirement of irreparable harm, the Commission finds that it is met, since the possible impact on the rights to life and personal integrity constitute the maximum situation of irreparability.

V. BENEFICIARIES

113. The Inter-American Commission declares that the beneficiaries are: (1) María Eugenia Monagas de Paris, (2) Larissa Ortigoza Monsalve, (3) Gina Vittoria Massimo Alcalde, (4) Nepmari Zambrano Noguera, (5) Johnny Ceccato Castellanos, (6) Román Tovar Zambrano, (7) Ligia Elejalde Carabali, (8) Humberto Ávila Henríquez, (9) Yakeisy Longa Rivero, (10) Eliana Ruiz Garcia, (11) Esther Judith Montero Larios, (12) Roel Díaz Velasco, (13) Nieves Yelitza Seijas Pelayo, (14) Rita Mayela García Peña, (15) Beatriz Aurora Moratinos Oronoz, (16) Crismary Johana Reyes Méndez, (17) Tatiana Pérez De Chaparro, (18) Sally Gordon De Madrid, (19) María Aguila Prato and (20) Lourdes Verenzuela Mavares, who are duly identified in this matter.

VI. DECISION

114. The Inter-American Commission on Human Rights considers that the present matter meets *prima facie* the requirements of seriousness, urgency and irreparable harm contained in Article 25 of its Rules of Procedure. Consequently, the Commission requests that the State of Venezuela:

a) take the necessary measures to protect the life, personal integrity and health of the beneficiaries, by adopting the immediate measures that enable access to adequate medical treatment, including the necessary medications, in accordance with what has been ordered by the corresponding physicians, as well as the diagnoses and tests that allow for the periodic evaluation of their health status, according to the applicable international standards.

115. The Commission requests as well that the State of Venezuela report, within 15 days from the date of this resolution, on the adoption of the precautionary measures requested and to update that information periodically.

116. The Commission emphasizes that, in accordance with Article 25 (8) of its Rules of Procedure, the granting of this precautionary measure and its adoption by the State do not constitute a prejudgment on any violation of the rights protected in the applicable instruments.

117. The Commission instructs the Executive Secretariat of the IACHR to notify this resolution to the State of Venezuela and the applicants.

118. Approved on January 7, 2021, by: Joel Hernández García, President; Antonia Urrejola Noguera, First Vice-President; Flávia Piovesan, Second Vice-President; Margarette May Macaulay; Edgar Stuardo Ralón Orellana; and Julissa Mantilla Falcón, members of the IACHR.

María Claudia Pulido
Acting Executive Secretary