

**Report on Children and Adolescents hospitalized
or with chronic diseases in Venezuela.
The J.M de los Ríos Children's Hospital Case**



Important Note: Article 6 of the International Covenant on Civil and Political Rights and points 2, 3, 30 and 64 of Observation 36 are violated.

This report presented by Prepara Familia, seeks to make visible the situation of children and adolescents hospitalized or with chronic diseases and the violation of their right to life due to the sanitary conditions of the country, specifically in the Hospital J. M. de los Ríos (National Reference Center that receives children and adolescents from all over the country), in the context of the Complex Humanitarian Emergency (CHE), the effects of the COVID19 pandemic and post - Covid. The reporting period is from 2016 to August 2023. The report focuses on the violations of the right to life of children and adolescents, who receive a differentiated burden in the face of the emergency they are experiencing.

The NGO Prepara Familia presents this report¹:

Prepara Familia is a civil society organization founded in 2008 that accompanies and defends the rights of children and adolescents hospitalized in public hospitals, in extreme poverty and defends the rights of women who perform care work. We have three lines of action: 1) The defense of the human rights of hospitalized children and adolescents, in national and international instances; 2) The development of programs of care, assistance, and monitoring for hospitalized children and adolescents and those who attend consultations in hospitals and 3) The development of programs of care, accompaniment, and defense of the human rights of women caregivers in public hospitals.

¹ <https://preparafamilia.org/>

I. Context

1. The J.M. de los Ríos Hospital is the most important pediatric health center in Venezuela, since it gathers thirty-four (34) specialty services, and treats children and adolescents from all over the country. However, neglect by government authorities has caused this national reference medical center to be in too poor of a condition to care for children and adolescents; to date, several services have been closed. In 2017, an infectious outbreak that could have been avoided, and the lack of antibiotics caused the death of ten children and adolescents in the nephrology service of the Hospital, leading to a situation of risk for the other children who were hospitalized or receiving dialysis in the service². For that reason, on December 21, 2017, the civil organizations, Prepara Familia and CECODAP, requested precautionary measures before the IACHR, which were granted on February 21, 2018³.

2. In October 2018, we requested the extension of measures for the children and adolescents of 13 services of the same Hospital (Cardiology Service, (ii) Hematology Service, (iii) Pneumology Service, (iv) Medicine 2 Service, (v) Medicine 3 Service, (vi) Anatomic Pathology Service, (vii) Breastfeeding Center or Specialized Care and Breastfeeding Training Medical Service, (viii) Outpatient and Triage Service, (ix) Neurosurgery Service, (x) Comprehensive Pediatric Service- Healthy Child, (xi) Nutrition, Growth and Development Service, (xii) Adolescent Medicine Service, and (xiii) Pediatric Neurology Service) which were granted on August 21, 2019⁴.

3. On August 06, 2020, the IACHR extended the precautionary measure initially granted on February 21, 2018, for Katherine Martinez, director of Prepara Familia, due to the fact that she is in a situation of risk because of her work as a human rights defender on behalf of children at the José Manuel de los Ríos Children's Hospital. However, to date, the Venezuelan State has not complied with any of the measures to improve the situation⁵.

II. Suspension of the Organ Procurement Program

4. On June 1, 2017, the organ procurement program was suspended in the country due to the lack of immunosuppressants that would guarantee the viability of transplants. Last June 1, 2023, marked six (6) years since the suspension of the Organ Procurement and Transplantation System and it is estimated that more than 1800 people have not been

² <https://efectococuyo.com/salud/cidh-solicita-al-gobierno-investigar-causas-de-brote-infeccioso-en-nefrologia-del-j-m-de-los-rios/>

³ <https://www.oas.org/es/cidh/decisiones/pdf/2018/8-18mc1039-17-ve.pdf>

⁴ <http://www.oas.org/es/cidh/decisiones/pdf/2019/43-19MC1039-17-VE-Ampliacion.pdf>

⁵ <http://www.oas.org/es/cidh/decisiones/pdf/2020/42-20MC1039-17-VE-Ampliacion.pdf>

able to be transplanted from deceased donors, of which approximately 200 correspond to children and adolescents on waiting lists⁶.

5. 25 children and adolescents who are part of the hematology service of the J.M. de los Ríos Hospital need a Bone Marrow Transplant and there is no effective response for them. Additionally, 14 young people who spent their childhood and adolescence waiting for an answer continue without receiving one. There are children and adolescents waiting for a liver transplant who have migrated to other countries looking for a solution.

6. Children and adolescents are especially vulnerable and have the right to be transplanted with absolute priority. However, currently, they are at serious risk of dying or have already died, as evidenced by the high rate of deaths that have occurred in the Hospital J.M de los Ríos. Only in the nephrology service from 2017 to August 2023, eighty (80) children and adolescents have died product of complications, irregular supply of antibiotics, and failures in dialytic treatment, among other causes. Mothers have protested at the doors of the hospital denouncing this situation, without getting a response from the Venezuelan State. The Venezuelan Society of Nephrology since 2017 has estimated that more than 70% of the hemodialysis units have decreased their operational capacity due to equipment maintenance problems, and lack of supplies or basic services.

7. On April 21, 2021, adolescents and young people suffering from chronic diseases and waiting for a transplant, requested a public hearing before the IACHR to make their situation visible; the hearing was granted and was held on June 30, 2021, in which they demanded that their fundamental rights to health, food, and a dignified life be fulfilled⁷.

8. On November 30, 2022, a live-to-live kidney transplant operation was performed at the J.M. de los Ríos Hospital (these transplants were never suspended, they were stopped because the State could not guarantee the anti-rejection drugs) without guaranteeing the adolescent the immunosuppressant protocol or the necessary services to perform an operation of this type. Consequently, the organizations Prepara Familia, Amigos Trasplantados, and Codevida presented a communiqué that was signed by 70 civil society organizations to denounce the precarious conditions in which the operation was performed and the risk to the children.⁸ From November 2022 to August 2023 only one live-to-live transplant has been performed in this hospital.

9. Last June 1, 2023 marked six (6) years since the suspension of the Organ Procurement System (SPOT), Venezuelans suffering from diseases that require an organ transplant completed six (6) years without the possibility of such a solution. Many could no longer wait and died.⁹

⁶<https://efectococuyo.com/salud/en-4-anos-no-se-hicieron-960-trasplantes-por-suspension-del-programa-de-procura-de-organos-alerta-ong/>

⁷<https://www.youtube.com/watch?v=pAjuWaev9pg&t=29s&pp=ygVQY2lkaCBhdWRpZW5jaWEgcHVibGljYSBzb2JyZSBhZG9sZXNjZW50ZXMGZW4gZXNwZXJhIGRIIHRyYXNwbGFudGVzIGVuIFZlbnV6dWVsYSA%3D>

⁸ https://cepaz.org/documentos_informes/70-osc-se-pronuncian-con-motivo-de-la-realizacion-del-trasplante-renal-de-vivo-a-vivo-en-el-hospital-j-m-de-los-rios/

⁹ <https://runrun.es/noticias/502638/a-seis-anos-suspendido-ong-exigen-reactivar-el-programa-de-trasplantes-en-venezuela/>

III. Status of the Hospital Infrastructure

10. Since 2016, the deterioration of the hospital infrastructure of the J.M de los Ríos Hospital has been increasing. Lack of maintenance, elevators that do not work, construction projects that do not comply with international standards have caused the facilities to care for children to deteriorate¹⁰.

11. The Hemodialysis Unit of the J.M. de los Ríos is the only unit in the country that provides service for children weighing less than 10 kilos, it has fifteen (15) machines of which, due to failures and lack of maintenance, only seven (7) or nine (9) work depending on the day, which affects the number of hours and days that the children must receive hemodialysis, putting their lives at risk.

12. Due to staff failures and lack of diagnostic equipment, lack of basic services, lack of decent salaries, and failure in the supply of medicines and supplies, the following services of the Hospital have been closed permanently: Cardiology Service¹¹, Neurology Service¹², Intensive Care Service¹³ and the technical closure of the Breastfeeding Center Mi Gota de Leche¹⁴. In addition, we must add that the Central Laboratory provides services in an irregular manner due to reagent failures¹⁵.

13. The hematology service in which children and adolescents with hematological diseases receive their chemotherapy protocol and which has an operating room to perform lumbar punctures, biopsies, etc., has had its air conditioning out of order for 10 months. The hemodialysis unit of the nephrology service has serious problems with the air conditioning and so do several services of the hospital, complicating the basic diseases of the children and adolescents due to the proliferation of bacteria.

IV. Medical Equipment and Reagents Status

14. The J.M. de los Ríos Hospital has no tomograph or resonator. The craniotome is damaged and each service has a list of equipment without service, due to the lack of preventive and corrective maintenance. Likewise, there is only one portable X-ray machine, which provides irregular service and is out of order most of the time. This health center has no reagents in its central laboratory and patients' families must have their laboratory tests done in private clinics. The laboratory of the nephrology service of the J.M. de los Ríos has not been functioning for approximately seven (7) years so special studies according to the pathology of the children cannot be done in the hospital¹⁶.

¹⁰ <https://provea.org/actualidad/derechos-sociales/salud/los-ninos-del-hospital-j-m-de-los-rios-siguen-muriendo-y-se-mantienen-a-la-espera-de-que-garanticen-sus-derechos/>

¹¹ https://www.youtube.com/watch?v=OpowFYy1_dQ

¹² <https://cronica.uno/cierre-del-servicio-de-neurologia-del-j-m-de-los-rios-deja-en-riesgo-a-mas-de-500-pacientes/>

¹³ <https://efectococuyo.com/salud/cierra-unidad-de-terapia-intensiva-del-jm-de-los-rios/>

¹⁴ <https://efectococuyo.com/salud/servicio-lactancia-materna-jm-de-los-rios-cierre-tecnico/>

¹⁵ <https://cecodap.org/en-seis-decadas-el-j-m-de-los-rios-se-convirtio-en-un-hospital-menguado-por-la-desidia/>

¹⁶ <https://cecodap.org/el-deterioro-del-hospital-jm-de-los-rios-cobra-con-muerte-de-ninos/>

15. The lack of reagents to perform serology tests on blood has often paralyzed surgeries throughout the country. Without serological tests, the Municipal Blood Banks - in charge of supplying tissue to hospitals - cannot rule out the presence of diseases such as HIV or hepatitis C in donations. Additionally, the reduction of staff and hematologists due to low salaries and migration has complicated the transfusions that children receive, as well as the lack of blood bags and transfusion equipment¹⁷. On June 14, 2023 (World Blood Donor Day), medical societies and civil society organizations held a press conference and a communiqué specifying the serious situation of the Blood Banks in the country¹⁸.

V. Provision of Medicines, Supplies and Vaccines

16. One of the main consequences of the Complex Humanitarian Emergency has been the decrease in the importation of medicines needed in the hospital network, which especially affects low-income patients who cannot acquire them outside the public system or bring them from abroad.

17. All the services of the J. M. De los Ríos Hospital have failures in the supply of medicines and supplies for each pathology. The NNAs cannot count on being provided with the complete protocols of medicines for cancer treatment, the NNAs who suffer from pulmonary hypertension do not have the protocol of medicines they require, the NNAs who were transplanted before 2017 do not get the complete protocols of the anti-rejection medicines (the immunosuppressants)¹⁹, this situation has been repeated for several years.

18. Supplies of medicines required for dialysis, such as iron, erythropoietin, and vitamin B12, are not in constant supply and when mothers protest and demand their provision, they are sent irregularly.

19. The provision of medical supplies continues to be deficient; the hospitals do not have a regular supply of injectors, helmets, macro droppers, transfusion equipment, and these supplies are often obtained through the children's families²⁰.

There is still an irregular supply of vaccines and in general, there is a low vaccination coverage in the country. Vaccines are often in short supply at the J.M. de Los Ríos Hospital, including at other hospitals, and this is an obstacle that limits the timely vaccination process, Rotavirus and pneumococcal vaccines have not been administered in public centers for at least five years²¹.

VI. Public Services Status

¹⁷ <https://efectococuyo.com/salud/bancos-de-sangre-fallas-reactivos-venezuela-menos-donantes/>

¹⁸ <https://humvenezuela.com/wp-content/uploads/2023/06/RUEDA-DE-PRENSA-BANCO-DE-SANGRE.pdf>

¹⁹ <https://efectococuyo.com/salud/medicos-y-madres-de-pacientes-exigen-insumos-para-el-hospital-j-m-de-los-rios-12mar/>

²⁰ <https://efectococuyo.com/salud/denuncian-falta-de-inyectadoras-y-equipos-para-transfusiones-de-sangre-en-el-j-m-de-los-rios/>

²¹ <https://prodavinci.com/venezuela-retrocedio-sus-coberturas-vacunales-durante-2021-muestran-datos-de-oms-y-unicef/>

20. The serious situation of public utilities directly affects the right to health of children. Electricity outages and irregular water service prevent the operation of the equipment necessary for hospital care. Likewise, the limited access to gasoline for the transportation of patients and medical personnel, as well as diesel for the operation of power plants.

21. The interruption of water service places hospitalized children at serious risk. In the midst of the pandemic, in which the first hygiene measure was to wash hands with soap and water, hospitals have remained without regular water service, proliferating bacteria and the risk of contamination, and when the service is suspended, bathrooms are closed.²²

22. Closed bathrooms have a differentiated impact because they prevent girls and adolescents from meeting the minimum requirements for personal and menstrual hygiene. In all public hospitals in the country, there are still failures in the supply of electricity. In the J.M. de los Ríos Hospital, although two power plants were installed, they do not cover the hospitalization tower or the isolation tower, and when there are failures in the power supply, the children's rooms are left in darkness and the girls and adolescents are at greater risk.

VII. Status of Hospital Food

23. The children and adolescents who are hospitalized at the J.M. de Los Ríos Hospital do not receive adequate food in the quality and quantity necessary according to their health condition. On many occasions, the mothers of the patients have reported that the food is repetitive, indicating that they are only served rice with some type of grain and arepa without filling²³.

24. Infants, and children of women with HIV do not receive infant formula. In addition, there continues to be a failure to provide the minimum nutritional supplements according to the protocols of care for healthy children and for special diets. Furthermore, children with malnutrition do not receive supplements or special nutritional formulas. Currently, 30% of Venezuelan children are stunted.

25. On April 05, 2018, the Ministry of Health suspended food for the Women Caregivers of children hospitalized at the J.M de los Ríos²⁴.

VIII. Health Personnel

²² <https://efectocucuyo.com/salud/jm-de-los-rios-recibe-a-ninos-con-covid-19-en-medio-de-fallas-de-servicios/>

²³ <https://efectocucuyo.com/salud/arepa-y-arroz-blanco-comen-ninos-en-j-m-de-los-rios/>

²⁴ <https://www.civilisac.org/alertas/comunicado-117-ong-e-individuales-exigen-respuesta-urgente-sobre-la-suspension-de-la-alimentacion-a-las-mujeres-cuidadoras-de-los-ninos-ninas-y-adolescentes-del-hospital-jm-de-los-rios>

26. The migration of physicians and low salaries have significantly affected services in the country's hospitals; for example, most hospital services are working with approximately 60% of the staff.

27. The salaries of doctors and health personnel, in general, are the lowest in the region, they receive approximately twenty to thirty dollars per month depending on the position. Additionally, they have been paid a bonus since the beginning of the year 2023 called an economic war bonus of approximately thirty (30) dollars which is not part of their social benefits, in any case, the amount received is very low.²⁵

28. The nursing staff is also scarce. In the J.M. de los Ríos hospital, for the morning shift, there are only two nurses for the hospitalization and hemodialysis area; for the afternoon shift there are three nurses, and in the night shift the situation is much more precarious; since sometimes there are no nurses and they must send nurses from other services who do not have the necessary experience in the care of children with different types of pathologies.

IX. Anatomic Pathology Service

29. The children who die in the J.M. de Los Ríos Hospital and in the pediatric units of the country are not treated with dignity, due to the failures and conditions of the pathological anatomy services. When several children die in a short period of time, the services collapse.

30. When children die, women and families do not receive any support from the hospital management or the State. They are left on their own with the help of very few civil society organizations to accompany them in the mourning, wake, burial, cremation, obtain resources to pay for funeral services, and make arrangements for the transfer of the bodies to the interior of the country.

X. Epidemiological Bulletin

31. Without official information it is not possible to generate effective public policies. Epidemiological bulletins in the country have not been released since the first week of May 2017, when the MPPS published on its website the last bulletin corresponding to the week from December 25 to 31, 2016

32. The disclosure was accidental and brought about the dismissal of Antonieta Caporale, who was the head of the Ministry. That bulletin set off alarms and revealed a setback of more than a decade in infant mortality: in 2016, 11,466 children died, 30% more than in 2015, of which 5,890 were girls. No such bulletin has been issued since that date.

XI. Consequences of the COVID-19 Pandemic

33. In the pediatric units of the country's public hospitals, more attention was given to children and adolescents with COVID-19 symptoms than to children and adolescents with chronic, nephrotic, hematological, and oncological diseases, who did not receive the attention they required, thus putting their own underlying disease at risk.

²⁵ <https://eldiario.com/2020/08/08/medico-venezuela-pandemia-bajos-salarios/>

34. Cleaning materials were not available, and much fewer biosafety protocols were followed. In this regard, soap, gloves, and antibacterial gel were not provided for the personnel, and masks were only provided once every three days, which increased the risk of infection by COVID-19²⁶.
35. At the J.M. de los Ríos Hospital, health and administrative personnel were vaccinated against COVID-19. However, it is important to note that priority was not given to female caregivers who were at the bedside of their hospitalized children or to adolescents with chronic pathologies who were hospitalized or receiving outpatient treatment at the Hospital.
36. A significant number of children and adolescents who received outpatient treatment at the J.M. de los Ríos Hospital were unable to continue attending to receive their chemotherapy procedures, and transfusions, since the beginning of the quarantine, due to the high costs they had to pay in dollars to travel and additionally due to the lack of public transportation, gasoline and lack of cash.
37. Since the beginning of the State of Alarm, the children and adolescents hospitalized in the J.M. de los Ríos Hospital did not receive hospital education. Before the pandemic, they received very few hours taught by teachers who received a very low salary and most of them have been resigning.
38. In the pediatric units of the country's public hospitals there is no recreation department; consequently, in some hospitals, some private foundations assume part of this role. From the beginning of the quarantine, since access was restricted, the children and adolescents did not receive attention from any type of cultural or recreational program.

XII. Recommendations to the Venezuelan State

39. Guarantee the availability of public services such as drinking water, electricity, gas, and telephony in the country's public hospitals, with special attention to the pediatric units of the country's public hospitals.
40. To reactivate the Organ and Tissue Procurement System in the country as well as to constitute bone marrow transplant units that comply with the protocols established by the WHO.
41. To publish health bulletins with exhaustive data on health and nutrition, broken down by sex, age, and pathology, of the children and adolescents who attended public hospitals that allow the establishment of adequate public policies with an impact on health.
42. Guarantee decent salaries for health personnel in public hospitals that allow them to practice their profession.
43. Guarantee that hospitalized girls and adolescents can comply with their normal and menstrual hygiene.
44. Guarantee vaccination coverage for children and adolescents in the Hospital and in general for the child population in the country.

²⁶ <https://cepaz.org/articulos/el-gremio-de-la-salud-amenazado-frente-al-covid-19/>

45. Respect for the guarantee of the right to life that continues to be violated in the health sector, especially for children and adolescents.