

# Epilepsy in Teenagers: A Study of the Combination of Contraception and Anti-Epileptic Drugs in Treatment

—Based on 32 Cases Collected at the Watsa General Reference Hospital, Haut-Uélé, Democratic Republic of the Congo

Lisimo Abwa Hilaire<sup>1\*</sup>, Ngbatala Amembu Michel<sup>1</sup>, Apenya Ababu Bienvenu<sup>1</sup>, Mambeizidra Ombazabo Jolie<sup>1</sup>, Malango Matungulu Julbert<sup>2</sup>, Mutwale Lubo George<sup>2</sup>, Kpakpo Nyange Yvette<sup>2</sup>, Eka Magasani Valentine<sup>2</sup>, Badhoka Kado Jerome<sup>1</sup>, Mosema Be Amoti Kizito<sup>1</sup>, Wembonyama Okitosho Stanislas<sup>3</sup>

<sup>1</sup>Department of Pediatrics, Uélé University Clinics, Isiro, Democratic Republic of the Congo

<sup>2</sup>Department of Pediatrics, La Baviere Health, Durba, Democratic Republic of the Congo

<sup>3</sup>Department of Pediatrics, Faculty of Medicine, University of Lubumbashi, Lubumbashi, Democratic Republic of the Congo

Email: \*lisimoka4@gmail.com

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## Abstract

**Introduction:** Epilepsy and its treatments require a number of precautions, both in terms of contraception and during pregnancy, due to the teratogenicity associated with common anti-epileptic drugs. To prevent these risks, we decided to conduct a study of our adolescent patients taking antiepileptic drugs in combination with SAYANA PRESS® PRESS (A long-acting and reversible contraceptive injection that women can administer themselves every 3 months), in whom we observed a complete cessation of seizures after two years of treatment. This allowed us to study the beneficial effects of combining SAYANA PRESS®, as a contraceptive with either carbamazepine or phenobarbital in adolescents aged 15 to 20 in the province of Haut-Uélé. **Materials and Methods:** This study employed both retrospective and prospective approaches, with a descriptive and analytical design. It targeted patients diagnosed with epilepsy based on clinical criteria (recurrent epileptic seizures) and paraclinical confirmation through electroencephalography (EEG). The study period extended from January 1, 2014, to December 31, 2023, covering a total duration of ten years. The study population consisted of adolescents aged 15 to 20 years who were followed at the pediatric outpatient clinic of the Watsa General Reference Hospital, located in Haut-Uélé province. All medical records of adolescent patients of childbearing age within this age range, diagnosed with epilepsy and

receiving treatment combining Sayana Press® contraception with an antiepileptic drug, were included. Data collection focused on epidemiological, socio-demographic, and electroclinical variables, using a standardized survey form. Statistical analyses were conducted with SPSS (Statistical Package for the Social Sciences), version 18. **Results:** From January 1, 2014, to December 31, 2023, we registered 305 pediatric neurology patients, including 158 cases of epilepsy (51.8%) and 32 cases of patients of childbearing age (15 to 20 years old), representing 20% of the total. The average age was 16 years. The patients were from rural areas (84%, 27 cases) and disadvantaged families (78%, 25 cases). Epileptic seizures were generalized in 68.7% (20 cases) and focal in 32.3% (12 cases). The majority of our patients had idiopathic epilepsy (90.6%, 29 cases). All were treated with a combination of antiepileptic drugs and Sayana Press®, contraceptive. Seizures had ceased definitively for 5 years in 81.25% (26 cases), for 2 years in 15.62% (5 cases), and 3.12% (1 case) continued to have seizures despite adhering to treatment. **Conclusion:** Epilepsy is common in Haut-Uélé province, accounting for 51% of neurological diseases at Watsa General Reference Hospital. Girls of childbearing age are affected by this disease in around 20% of cases. The combination of antiepileptic drugs and SAYANA PRESS®, contraception has a beneficial effect on the permanent cessation of seizures for 5 years in around 81.25% of cases, enabling more than 50% of adolescents to return to school, and for two years in 20% of cases. It is most prevalent in rural areas and among disadvantaged families, affecting more than 80% of cases.

### Keywords

Epilepsy and Adolescents, Public Health, Combination of Ae and Contraception, Haut-Uélé

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## 1. Introduction

Epilepsy is one of the most common serious chronic neurological diseases, affecting people of all ages worldwide. It is characterized by recurrent seizures. There are many causes of the disease [1].

More than 50 million people worldwide suffer from epilepsy, with over three-quarters of them living in low- and middle-income countries. It is estimated that there are 2.4 million new cases each year. Approximately 600,000 people are affected in France [1].

The prevalence of epilepsy in sub-Saharan Africa varies between 7 and 14.8% [1]-[3]. In Senegal, the prevalence of epilepsy was estimated at 14.2% in the suburbs of Dakar in 2001, with a frequency of 62.4% compared to other neurological disorders [4] [5].

In the Democratic Republic of Congo, the true extent of epilepsy is not well known, although several actions have been carried out by the WHO worldwide through the UN World Health Organization's Global Intersectoral Action Plan

[6] [7].

In Haut-Uélé province, the arrival of a pediatric neurologist has made it possible to set up a pediatric neurology unit at the WATSA General Reference Hospital, launch fixed, mobile, and outpatient consultation campaigns, and acquire an electroencephalogram (EEG) machine. In our region, as elsewhere in the world, people with epilepsy often face stigma and discrimination due to misconceptions and negative attitudes associated with the disease. Among other misconceptions are “possession by evil spirits”, the belief that “epilepsy is contagious”, and the assumption that it is a form of “madness”. Stigma leads to human rights violations and social exclusion. In some communities, children with epilepsy may not be allowed to attend school, and adults may be unable to find suitable employment or marry.

Treatment for epilepsy requires a number of precautions, both in terms of contraception and during pregnancy, due to the teratogenicity associated with common anti-epileptic drugs. To prevent these risks, we decided to conduct a study of our adolescent patients taking antiepileptic drugs in combination with SAYANA PRESS®, an injectable contraceptive [8], in whom we observed a complete cessation of seizures after two years of treatment. This allowed us to study the beneficial effects of combining SAYANA PRESS® as a contraceptive with either carbamazepine or phenobarbital in adolescents aged 16 to 20 in the province of Haut-Uélé.

## **2. Materials and Methods**

### **2.1. Study Type and Period**

This was a retrospective and prospective, descriptive and analytical study conducted from January 1, 2014 to December 31, 2023, covering a total duration of ten years.

### **2.2. Study Setting**

The study was carried out at the Watsa General Reference Hospital, located in Haut-Uélé province in the Democratic Republic of the Congo. This hospital serves as a referral center for the region, which is predominantly rural and faces significant health challenges, including limited access to specialized care and medical resources.

### **2.3. Study Population and Sampling**

The study population consisted of adolescents aged 15 to 20 years who were followed at the pediatric outpatient clinic of the Watsa General Reference Hospital. All medical records of adolescent patients of childbearing age within this age range, diagnosed with epilepsy based on clinical criteria (recurrent epileptic seizures) and paraclinical confirmation (EEG), and treated with a combination of an antiepileptic drug including either carbamazepine or phenobarbital, and SAYANA PRESS® contraception, were included. Sampling was exhaustive, covering all eligible cases.

## 2.4. Data Collection

Data were collected using a standardized survey form. Information gathered included epidemiological and sociodemographic characteristics, as well as electro-clinical data.

## 2.5. Data Analysis

Statistical analysis was performed using SPSS (Statistical Package for the Social Sciences), version 18. Quantitative variables were described using means, absolute frequencies, and proportions. Comparisons of proportions were conducted using Pearson's chi-square test or Fisher's exact test, depending on the observed sample sizes. Descriptive analysis was performed to summarize the data, providing frequency distributions and mean values for each parameter. Bivariate analysis was subsequently conducted to assess associations between variables. For this purpose, odds ratios (ORs) were calculated along with their corresponding 95% confidence intervals (95% CI). Statistical significance was determined using a threshold of  $p < 0.05$ .

## 2.6. Ethical Considerations

This study was conducted in accordance with biomedical research ethics principles. Approval was obtained from the relevant ethics committee, and informed consent was secured from patients or their legal guardians. Anonymity and confidentiality of data were strictly maintained throughout the research process.

## 3. Results

**Table 1.** Study population characteristics (2014-2023).

Variable	n	%
Total pediatric neurology patients	305	100
Epilepsy cases	158	51.8
Patients aged 15 - 20 years	32	20.0
Mean age (years)	16	—
Rural origin	27	84.0

This **Table 1** presents the main characteristics of the pediatric neurology population studied during the period considered. Out of a total of 305 patients, more than half (51.8%) were followed for epilepsy, underscoring the significant burden of this condition within the cohort. Among them, 32 patients were adolescents aged 15 to 20 years, representing 20% of the sample, with a mean age of 16 years. The majority of patients originated from rural areas (84%, 27 cases), reflecting a geographical context characterized by limited access to specialized care. In addition, a high proportion (78%, 25 cases) belonged to disadvantaged families, highlighting the socio-economic vulnerability of this population.

**Table 2.** Clinical characteristics of epilepsy patients (n = 32).

Variable	n	%
Generalized seizures	20	68.7
Focal seizures	12	32.3
Idiopathic epilepsy	29	90.6
Treatment (AED + Sayana®)	32	100

The majority of patients experienced generalized seizures (68.7%, 20 cases), while a smaller proportion presented with focal seizures (32.3%, 12 cases) (**Table 2**), indicating that generalized forms were predominant in this cohort. Most patients were classified as having idiopathic epilepsy (90.6%, 29 cases), suggesting that structural or symptomatic causes were rarely identified. Importantly, all patients (100%) received treatment combining antiepileptic drugs (AEDs), carbamazepine or phenobarbital, with Sayana® contraceptive, reflecting a uniform therapeutic approach within this population. No difference was observed among patients treated with carbamazepine and those treated with phenobarbital. The clinical outcomes resulting from the combination of these two antiepileptic drugs with Sayana Press were similar in both groups.

**Table 3.** Seizure outcomes under treatment (n = 32).

Outcome	n	%
Seizure-free for five years	26	81.25
Seizure-free for 2 years	5	15.62
Persistent seizures despite treatment	1	3.12

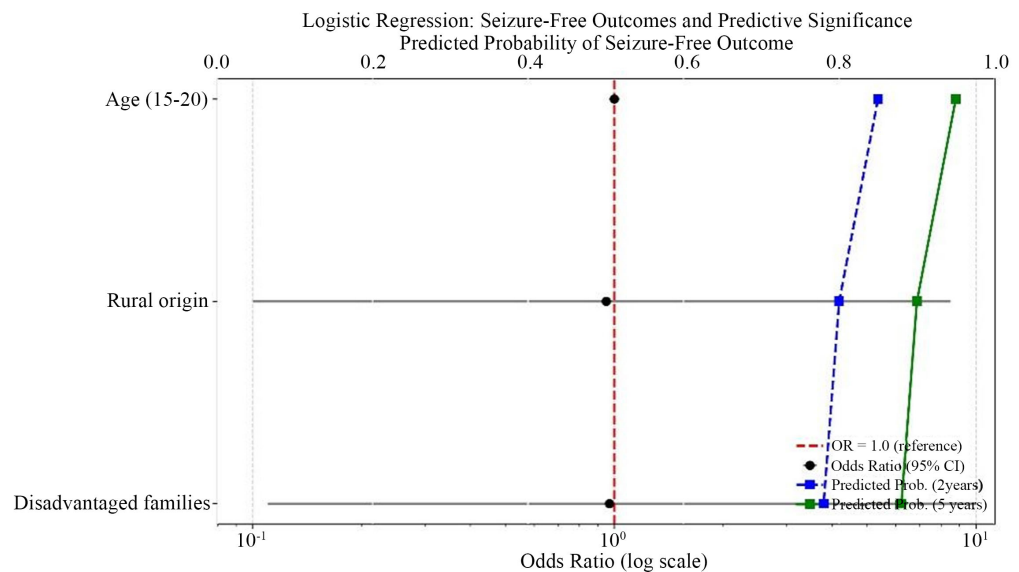
The data presented in **Table 3** demonstrate highly favorable long-term seizure outcomes among the study population. A substantial majority of patients (26/32; 81.25%) (**Table 3**) achieved complete seizure freedom for a period of five years, indicating sustained therapeutic efficacy and excellent long-term control. This proportion reflects not only the effectiveness of the treatment regimen but also the potential role of consistent adherence and possibly synergistic effects between antiepileptic drugs and adjunctive interventions. In addition, a smaller subset of patients (5/32; 15.62%) remained seizure-free for two years, suggesting that while seizure control was achieved, long-term stability may require extended follow-up or optimization of therapy. Importantly, only one patient (3.12%) continued to experience persistent seizures despite treatment, underscoring both the rarity of pharmacoresistance in this cohort and the overall robustness of the therapeutic approach. Taken together, these results highlight the predominance of favorable outcomes, with more than 96% of patients achieving at least two years of seizure freedom.

The vast majority of patients (81.25%) remained seizure-free for five years, while 15.62% achieved seizure freedom for two years, and only one patient

(3.12%) continued to experience seizures despite treatment (**Table 4**). When examining predictors, all patients were within the 15 - 20 years age group, which explains the neutral odds ratio (OR = 1.00). Rural origin was common (84%), and a disadvantaged family background was also frequent (78%). The odds ratios for rural origin (OR = 0.95, 95% CI: 0.10 - 8.50) and disadvantaged families (OR = 0.97, 95% CI: 0.11 - 9.00) were close to unity, with very wide confidence intervals. This indicates no statistically significant association between these characteristics and seizure outcomes.

**Table 4.** Epidemioclinical characteristics.

Characteristic	Seizure-free for 5 years (n = 26)	Seizure-free for 2 years (n = 5)	Persistent seizures (n = 1)	Total (n = 32)	OR [IC = 95%]
Age (15 - 20)	26 (81.25%)	5 (15.62%)	1 (3.12%)	32 (100%)	1.00
Rural origin	22 (84.6%)	4 (80.0%)	1 (100%)	27 (84.0%)	0.95 [0.10 - 8.50]
Disadvantaged families	20 (76.9%)	4 (80.0%)	1 (100%)	25 (78.0%)	0.97 [0.11 - 9.00]



**Figure 1.** Logistic regression: Seizure-free outcomes and predictive significance associated with predicted probability of seizure-free outcome.

The logistic regression results illustrated in **Figure 1** show that age (15 - 20 years), rural origin, and disadvantaged family background did not exert a significant influence on the likelihood of remaining seizure-free for five years, as their odds ratios (0.95 and 0.97) were close to 1 and the wide confidence intervals encompassed the reference value. The probability curves confirm that the majority of patients (over 80%) maintained long-term seizure freedom regardless of these socio-demographic factors. These findings suggest that, within this small cohort, social or geographic characteristics did not alter treatment effectiveness, and the stability of outcomes primarily reflects the therapeutic strength of the antiepileptic regimen.

## 4. Discussion

In our study, we recorded a frequency of 51.8% of epilepsy in the pediatric neurology consultation at the WATSA General Reference Hospital. This result is similar to that of other researchers, who found that more than 60% of epilepsy cases occur before the age of 20 [5] [9].

In our study, 84% of patients (27 cases) were from rural areas, and 78% (25 cases) were from disadvantaged families. These results are significantly higher than those found in 2001 by the Senegalese League Against Epilepsy and Lamine THIAM *et al.* [5] (70.9% and 60%).

In fact, in our study, the average time between the onset of seizures and consultation at our facility was 12 months [2 days - 96 months]. Thirty-six point five percent (36.5%) of patients had initially sought traditional treatment.

Epileptic seizures were generalized in 68.7% (20 cases) and focal in 32.3% (12 cases). Our results are comparable to those of several other African authors [5] [10] [11]. This could be explained by the relative scarcity of EEG equipment in our settings and the spectacular nature of generalized seizures. We relied more on videos taken by parents to establish the classification of seizures.

In terms of the syndromes, 90.6% (29 cases) were noted in our series of idiopathic epilepsies. MRI, the examination of choice for morphological exploration of the brain in epileptic children, is not yet available throughout the province, nor is CT scanning.

Girls of childbearing age are affected by this disease at a rate of 20%. The combination of antiepileptic drugs and SAYANA PRESS®, a contraceptive, has a beneficial effect on the permanent cessation of seizures for 5 years in 81.25% of cases (26 cases). No studies have been conducted on SAYANA's use in combination with antiepileptic drugs. The finding that no clinical difference was observed between patients treated with carbamazepine and phenobarbital when combined with Sayana Press suggests that progestin-based contraceptives may enhance the effectiveness of antiepileptic drugs. Progestins, through their neuroactive metabolites, are known to potentiate GABAergic inhibition and reduce neuronal excitability, thereby complementing the pharmacological action of antiepileptics in stabilizing seizure thresholds. This synergistic interaction is particularly relevant in women with epilepsy, where hormonal fluctuations can exacerbate seizure frequency, and consistent progestin exposure from long-acting formulations such as Sayana Press may help maintain therapeutic stability. These results are consistent with previous studies showing that progestins can positively interact with antiepileptic therapy, reinforcing the rationale for integrating contraceptive strategies into epilepsy management, especially in resource-limited and conflict-affected settings [12] [13].

Our observations during contraception in women with epilepsy who were repeatedly raped and returned with unwanted pregnancies, abortions, or miscarriages, and congenital malformations linked to the effects of antiepileptic drugs, led us to decide to put them on contraception with the support of The United

Nations Population Fund (UNFPA). Among adolescents who had started menstruating, a very positive finding was that after two years of administration of Sayana® [8] and antiepileptic drugs, we observed a definitive cessation of seizures a few years after these adolescents stopped taking antiepileptic drugs. We therefore wanted to share this observation with other researchers.

### Author Contributions

LAH: Conceptualization, study design, data collection, manuscript drafting, NM: Data analysis, interpretation of results, critical revision of the manuscript, LAH and AB: Patient recruitment, clinical data acquisition, contribution to methodology, MG, MJ and KNY: Statistical support, preparation of tables and figures, literature review, drafting of background and discussion sections, clinical supervision, validation of neurological diagnoses, contribution to patient follow-up and treatment documentation, EV, BJ and MK: Assistance in data management and quality control, support in manuscript editing and formatting for submission, contribution to interpretation of clinical outcomes, WS: Senior supervision, final approval of the manuscript.

### Conflicts of Interest

The authors declare that they have no conflicts of interest related to this study.

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