Oregon Health & Science University
School of Medicine

# Scholarly Projects Final Report

**Title** *(Must match poster title; include key words in the title to improve electronic search capabilities.)*

Continuation vs Cessation: Hormonal Birth Control in Idiopathic Intracranial Hypertension (IIH)

**Student Investigator's Name**

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**Date of Submission** *(mm/dd/yyyy)*

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**Project Course** *(Indicate whether the project was conducted in the Scholarly Projects Curriculum; Physician Scientist Experience; Combined Degree Program [MD/MPH, MD/PhD]; or other course.)*

Scholarly Project Curriculum

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Neuro-ophthalmology

# Scholarly Project Final Report

**Concentration Lead's Name**

Dr. Ladawna Gievers

**Project/Research Question**
In patients with idiopathic intracranial hypertension (IIH) who are taking hormonal birth control (HBC) at time of diagnosis, does discontinuation of HBC assist with faster remission or improvement of IIH related outcomes?

**Type of Project** *(Best description of your project; e.g., research study, quality improvement project, engineering project, etc.)*
Research Study

**Key words** *(4-10 words describing key aspects of your project)*
Idiopathic Intracranial Hypertension, Hormonal Birth Control Cessation

**Meeting Presentations**
*If your project was presented at a meeting besides the OHSU Capstone, please provide the meeting(s) name, location, date, and presentation format below (poster vs. podium presentation or other).*
N/a

**Publications** *(Abstract, article, other)*
*If your project was published, please provide reference(s) below in JAMA style.*
N/a

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No restrictions

# Scholarly Project Final Report

**Report:** *Information in the report should be consistent with the poster, but could include additional material. Insert text in the following sections targeting 1500-3000 words overall; include key figures and tables. Use Calibri 11-point font, single spaced and 1-inch margin; follow JAMA style conventions as detailed in the full instructions.*

## Introduction *(≥250 words)*

Idiopathic intracranial hypertension (IIH) is a rare medical condition defined by an increase in intracranial pressure resulting in bilateral optic disc edema (papilledema). It poses significant threat to patient vision if not treated promptly with a carbonic anhydrase inhibitor such as acetazolamide or, in refractory or severe cases, urgent optic nerve sheath fenestration, cerebral venous sinus stenting, or cerebrospinal fluid (CSF) diversion surgery. IIH is usually diagnosed when patients present with visual changes and chronic headaches, often in the context of recent weight gain.

Patients who develop this condition are most frequently obese females of childbearing age[1], though the condition can impact patients of all sexes and ages. Excess androgen levels have been proposed as a potential trigger for the condition due to their interplay with CSF production[2]. Further, hormonal birth control (HBC) may contribute to development of IIH symptoms in some patients[3]. Various forms of HBC have been implicated in patient weight gain[4], which has the theoretical potential to trigger or worsen IIH pathology. This stated, it is unclear if stopping HBC after IIH is diagnosed results in faster disease remission or overall improvement in the disease course[5]. Given the risks that pregnancy poses in patients with IIH[6], cessation of the patient's contraception may be more risky than beneficial. As a result, medical recommendation regarding HBC cessation in this patient population is made on an individual provider and patient level basis without robust scientific guidance.

The purpose of this study was to retrospectively review charts of patients who were on HBC when diagnosed with IIH, and to determine if cessation of their contraceptive medication assisted with earlier time to remission or improvement in their disease course.

## Methods *(≥250 words)*

We conducted a retrospective chart review in Epic of all female patients diagnosed with IIH at Oregon Health & Science University between January 1, 2011, and November 25, 2025. This date range was identified as electronic chart records prior to approximately 2011 were sparse. Patients eligible for study inclusion were using any form of hormonal birth control (HBC) at the time of diagnosis. Collected variables included HBC cessation date (if applicable), adverse events such as unplanned pregnancy, papilledema severity, time to papilledema resolution from disease onset, and treatment course.
Once data was collected from charts, patients were stratified into three groups: HBC continuation, cessation within six months of diagnosis, and cessation after six months of diagnosis. Patients were not further stratified by type of HBC due to low patient population size. A Kaplan Meier analysis compared time to remission between those who stopped and continued their HBC at disease onset. Of note, all patients who discontinued their HBC more than six months after IIH diagnosis reached remission of their IIH prior to discontinuation. As a result, they were included in the continuation group for the Kaplan Meier analysis.
A chi-square test assessed statistically significant differences between the three groups in regard to presence of a refractory disease course, as defined by surgical intervention, taper failure, never reaching remission, or disease flares. A post hoc power analysis was performed to assess study power given the low population size. A multivariate regression integrating variables such as BMI, papilledema severity and surgical intervention was not run due to the overall low power of the study.

**Results** *(≥500 words)*

Of 396 patients identified to have IIH seen at OHSU during the study time period, 65 had chart information available supporting HBC use at the time of their IIH diagnosis. 20 patients (30%) stopped their HBC within 6 months of their IIH diagnosis, as compared to 17 (26.2%) stopping at a later date and 28 (43%) continuing their HBC throughout disease course. The majority of patients (95%) stopping their HBC within 6 months of IIH diagnosis had clinical notes in their chart citing their new diagnosis as the reason for cessation. While not explicitly collected, cessation was frequently driven by the patient over provider recommendation. Table 1 below provides additional description of each patient population stratified by HBC cessation groupings.

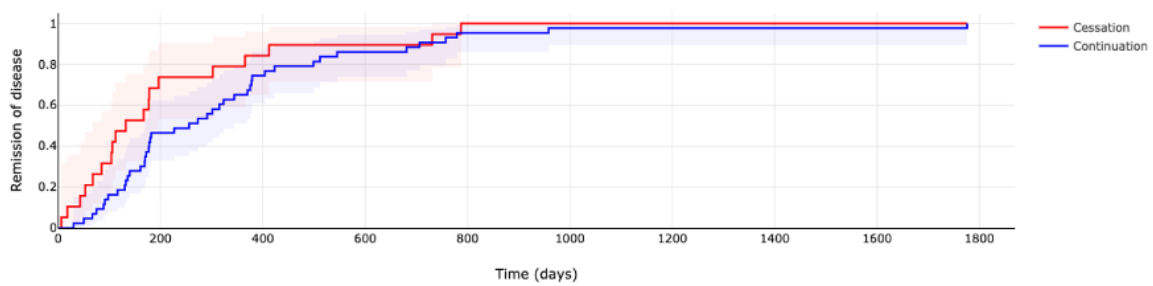
**Table 1. Description of patients depending on their timeline for HBC cessation**

| | Patients who stopped HBC within < 6 months of IIH diagnosis | Patients who stopped HBC within > 6 months of IIH diagnosis | Patients who continued HBC |
|---|---|---|---|
| **Total Number of Patients (65)** | **20 (30%)** | **17 (26.2%)** | **28 (43%)** |
| Average age at IIH onset | 23.8 | 27.5 | 25.8 |
| Average BMI at IIH onset | 39.4 | 30.15 | 43.5 |
| Reason for discontinuation of HBC was IIH | 19 (95%) | 8 (47%) | 0 (0%) |
| Number with documented Grade 3 or 4 Papilledema | 6 (30%) | 5 (29.4%) | 7 (25%) |
| Number with refractory IIH | 9 (45%) | 7 (41.1%) | 12 (42%) |

The percentage of patients with refractory IIH disease course across the three cessation groups were similar at 45% (cessation within six months), 41.1% (cessation after six months) and 42% (continuation). A chi squared analysis of refractory disease rates amongst these three groups demonstrated no significant difference between groups ($\chi^2 = 0.06$, $p = 0.97$, Cohen's $w = 0.03$ demonstrating small effect size). Further analysis of odds ratios between groups demonstrated they had similar odds of developing refractory disease regardless of HBC continuation or cessation (OR of ≤6 months vs never stopped, 1.09 (95% CI 0.34–3.49)).

In regard to length to IIH remission, patients who stopped their HBC within six months of disease onset had a shorter time to remission as compared to patients who continued their HBC (244 days as compared to 335 days). In this analysis, patients who stopped their HBC greater than 6 months after disease diagnosis were included in the continuation group, as all reached disease remission prior to discontinuation of their HBC. Despite an apparent difference between groups in their average time to remission, this difference was not statistically significant. A Kaplan Meier analysis was performed, which can be found in Figure 1, demonstrating heavily overlapping 95% confidence intervals for these two groups.

Figure 1. Kaplan Meier curve for days to remission in patients who ceased or continued their HBC within 6 months of their IIH diagnosis




Other IIH related outcomes can be found in Table 2 below. Notably, 2 patients or 10% of patients stopping their HBC within 6 months of diagnosis, had unplanned pregnancies as a result of their cessation. They both ultimately had complications in their IIH disease course secondary to their pregnancies. Additionally, rates

of failed medication taper appeared higher in patients who continued their HBC (25%) compared to those who stopped (10% of within six months cohort, 23.5% of after six months cohort). However, it also appeared that flares were less common in those who continued with their HBC (28.5%) as compared to those who discontinued their HBC at some point (40%). Of note, the differences in these proportions were not assessed for statistical significance between groups.

**Table 2. IIH related outcomes comparing patients depending on their timeline for HBC cessation**

| | Patients who stopped HBC within < 6 months of IIH diagnosis | Patients who stopped HBC within > 6 months of IIH diagnosis | Patients who continued HBC |
|---|---|---|---|
| **Total Number of Patients (65)** | **20** | **17** | **28** |
| Unplanned pregnancy | 2 (10%) | 0 (0%) | 0 (0%) |
| Average number of days to full remission (SD) | 244.25[1] (221) | 299 (203) | 358 (362) |
| Conservative Management | 1 (5%) | 2 (11.8%) | 1 (3.6%) |
| High dose medical therapy | 5 (25%) | 3 (17.6%) | 2 (7%) |
| Surgical interventions | 3 (15%) | 0 (0%) | 6 (21.4%) |
| Flares | 8 (40%) | 7 (41.1%) | 8 (28.5%) |
| Number that never reached full papilledema resolution | 1 (5%) | 0 (0%) | 2 (7%) |
| Number requiring long term medical therapy (failed taper) | 2 (10%) | 4 (23.5%) | 7 (25%) |

[1]Three patients who discontinued their HBC after papilledema resolution were excluded from average

IIH is a rare disease process. This study focused on only a small portion of all patients at a single center diagnosed with this condition during an approximate 15-year period. Given the small sample size identified for study inclusion by our chart review, a post hoc power analysis was performed to identify if the study was significantly underpowered. The post hoc power was identified to be only 5%, whereas a study is ideally powered to approximately 80%. Given the low power of this study, no multivariate regression was performed.

## **Discussion** *(≥500 words)*

In this retrospective study of 65 patients with idiopathic intracranial hypertension (IIH) diagnosis while on HBC, we found no statistically significant differences in clinical outcomes between patients who discontinued hormonal birth control (HBC) and those who continued their therapy after IIH diagnosis. Specifically, time to remission as defined by resolution of papilledema, did not differ significantly between HBC cessation or continuation cohorts. Similarly, there was no observed difference in the proportion of patients who developed refractory disease. Calculated odds ratios comparing the likelihood of refractory disease among patients who stopped versus continued HBC were not statistically significant. However, these findings must be interpreted with caution given the study's extremely limited statistical power (5%), which substantially restricts the ability to detect anything other than large effect sizes.

Importantly, 10% of patients who discontinued HBC within six months of IIH diagnosis experienced an unplanned pregnancy. These pregnancies were associated with short-term worsening of IIH symptoms, although both patients ultimately experienced improvement in papilledema without visual deficit. This observation is consistent with prior literature suggesting that pregnancy may transiently exacerbate IIH related symptoms but does not appear to confer permanent visual risk[7]. When counseling patients considering cessation of their HBC in the setting of IIH, clinicians should discuss alternative contraceptive strategies, particularly for patients who are sexually active and at risk for unintended pregnancy. When considering the findings of this study, the potential risks associated with unplanned pregnancy may outweigh any theoretical benefit of discontinuing HBC. That stated, contraceptive planning is a shared decision-making process, and patient preferences are paramount in the discussion.

An additional consideration when interpreting the results of this study relates to the definition of remission in IIH. Remission is conventionally defined by the resolution of papilledema on fundoscopic examination, or essentially the stabilization of pathology threatening patient vision. However, many patients continue to experience debilitating headaches even after papilledema resolves. It is frequently unclear if these findings are secondary to the patient's IIH disease course or if they have a concurrent migraine disorder. In clinical practice, headaches related to IIH most commonly persist until substantial weight loss is achieved[8] through lifestyle modification or, in patients with body mass index (BMI) greater than 35, bariatric surgery. Therefore, while papilledema resolution serves as an objective marker of disease control, it may not fully capture patient-centered outcomes or quality-of-life measures in this disease process.

This study is subject to several significant limitations. Foremost, the small sample size resulted in a markedly underpowered analysis. With only 5% power, the study would be capable of detecting only very large differences of approximately 30% or greater between groups. The limited sample size also precluded multivariable regression modeling, which in a larger cohort would be important to adjust for potential confounders such as BMI, weight change, or comorbid conditions that may influence disease trajectory. Additional limitations include incomplete documentation within patient charts, including missing ophthalmologic examination findings and papilledema severity grading. In cases where documentation was insufficient to confirm diagnostic criteria, patients were excluded, potentially introducing selection bias. Finally, all forms of HBC were analyzed as a single cohort. Although necessary due to sample size constraints, this grouping may obscure differential effects of specific HBC formulations on IIH disease course.

Future studies looking to explore HBC use in patients with IIH should aim to increase the study population, likely through expansion of the study to pull findings from multiple clinical sites. If an association continues to be suspected, prospective studies would also improve study strength.

**Conclusions** *(2-3 summary sentences)*

In this study discontinuation of HBC in patients with new onset IIH was not associated with statistically significant difference in time to remission or development of refractory disease, however these findings are significantly limited by low statistical power secondary to a small study population. Cessation of HBC within six months of diagnosis resulted in 10% of patients having unintended pregnancy, underlining the importance of contraceptive counseling at time of cessation.

**References** *(JAMA style format)*

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