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ROYAL MAXIM PALACE KEMPINSKI, CAIRO

Challenges in Paediatric Idiopathic Intracranial Hypertension

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Why paediatric IIH is hard

- Symptoms are **common**; **serious** causes are rare but must be **excluded**.
- The definitive work-up (**imaging** + **LP**) can be **delayed**, technically **difficult**, or require **GA**.
- Monitoring is **tricky**: objective function tests depend on age/cooperation; swelling can change quickly.
- Care is **multidisciplinary** (ophthalmology, paediatric neurology, radiology, anaesthetics).

Safety
Don't miss secondary causes

Vision
Detect early functional loss

Experience
Minimise invasive tests where possible

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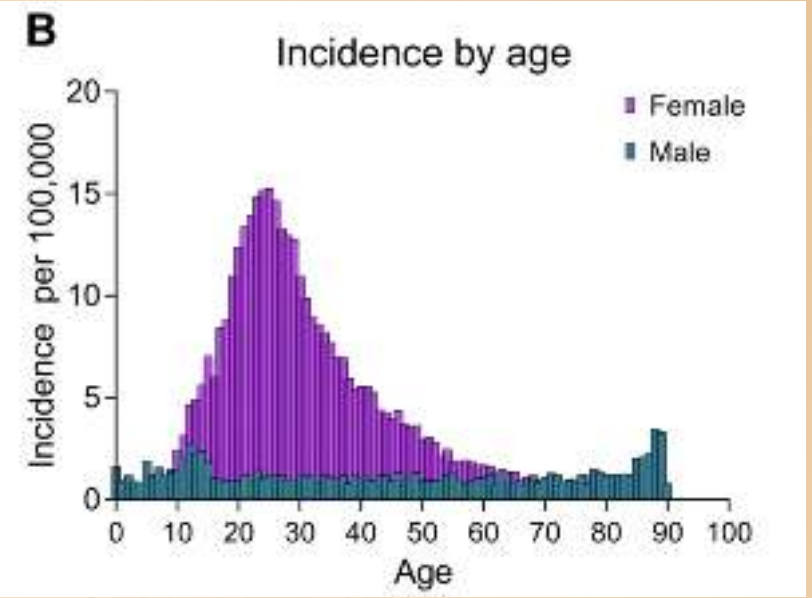
Paediatric IIH: epidemiology

- **Bimodal** age distribution– rare in young children (often non-obese, look for secondary causes)
- incidence in the paediatric population**: 0.17-1.32** per 100.000 children (**0.71** per 100.000 in ages 1–16 years)
- **Pre-pubertal**: M ≈ F, 30 % obese;
- **Post-pubertal (12-15)** mirrors adult female-obesity link.
  - **4.18** per 100.000 in **boys**
  - **10.7** per 100.000 in **girls**



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Victorio MC, Rothner AD. Diagnosis and treatment of idiopathic intracranial hypertension (IIH) in children and adolescents. *Curr Neurol Neurosci Rep* 2013;13. 27
Sinclair AJ, Burdon MA, Nightingale PG, *et al*. Low energy diet and intracranial pressure in women with idiopathic intracranial hypertension: prospective cohort study. *BM*

Symptoms and diagnosis

IIH symptoms

- Headache (increasingly severe and frequent) (76-94%)
- Visual obscuration's (darkening of the vision) (68-72%)
- Pulsatile tinnitus (52-61%)
- Back pain (53%)
- Dizziness (52%)
- Neck pain (42%)
- Blurred vision (32%)
- Cognitive disturbance (20%)
- Radicular pain (19%)
- Diplopia (typically horizontal) (18%)

Friedman's criteria

IIH Diagnostic criteria

A. Papilloedema
B. Normal neurological examination (except sixth cranial nerve palsy)
C. Neuroimaging: normal brain parenchyma (no hydrocephalus, mass, structural lesion or meningeal enhancement). Venous thrombosis excluded in all.
D. Normal CSF constituents
E. Elevated lumbar puncture pressure ≥ ~~25cmCSF~~

28 cm H_2O

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Mollan, S. P., et al. (2018). Idiopathic intracranial hypertension: consensus guidelines on management. *Journal of Neurology, Neurosurgery & Psychiatry, 89*(10), 1088–11

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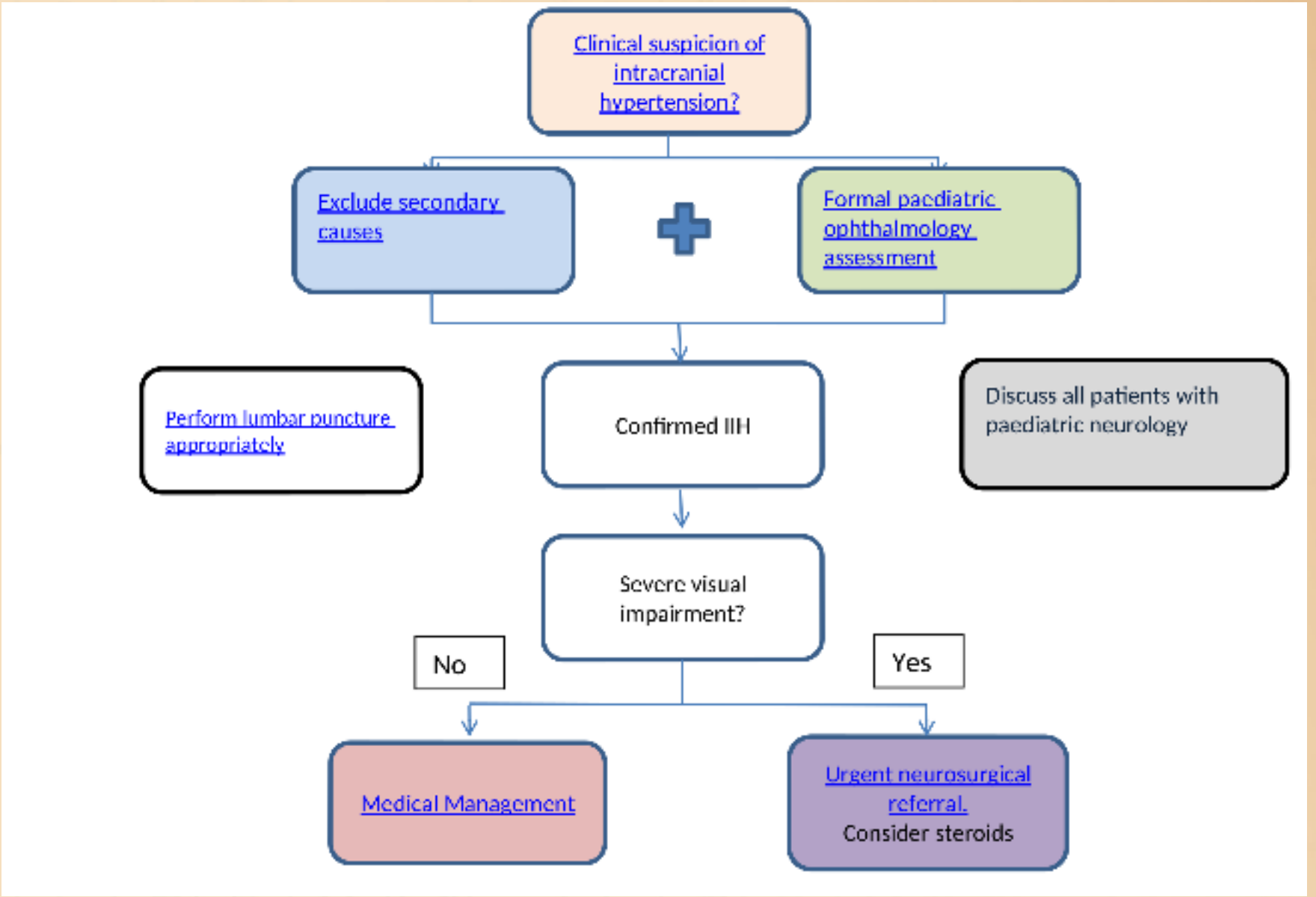
OUH pathway



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Exclude secondary causes

“Idiopathic” is a diagnosis of exclusion — especially in pre-pubertal children

Vascular / infective / systemic

- **Cerebral venous sinus thrombosis or other venous abnormalities**
- Middle ear/mastoid infection
- Hypercoagulable state
- Raised right heart pressure / SVC syndrome / AV fistula
- Reduced CSF absorption (previous intracranial infection or SAH)
- **Anaemia**, renal failure, **vitamin D deficiency**
- Sleep apnoea
- Genetic syndromes: Turner, Down syndrome

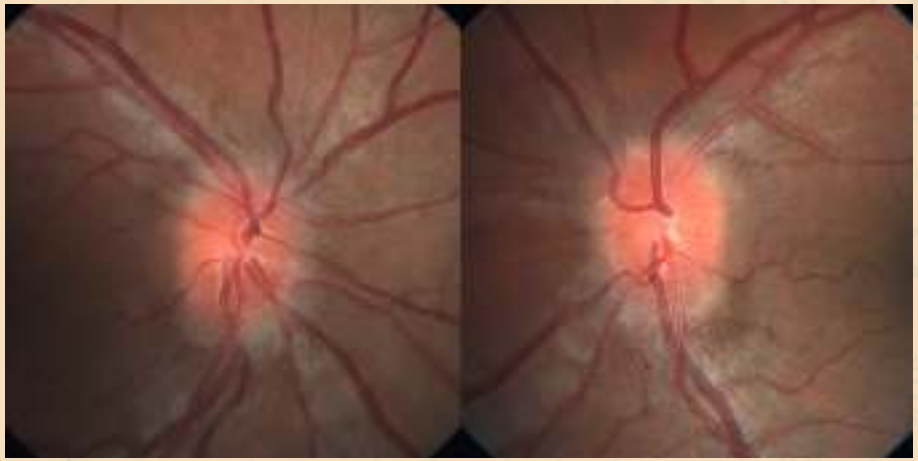
Drugs & endocrine triggers

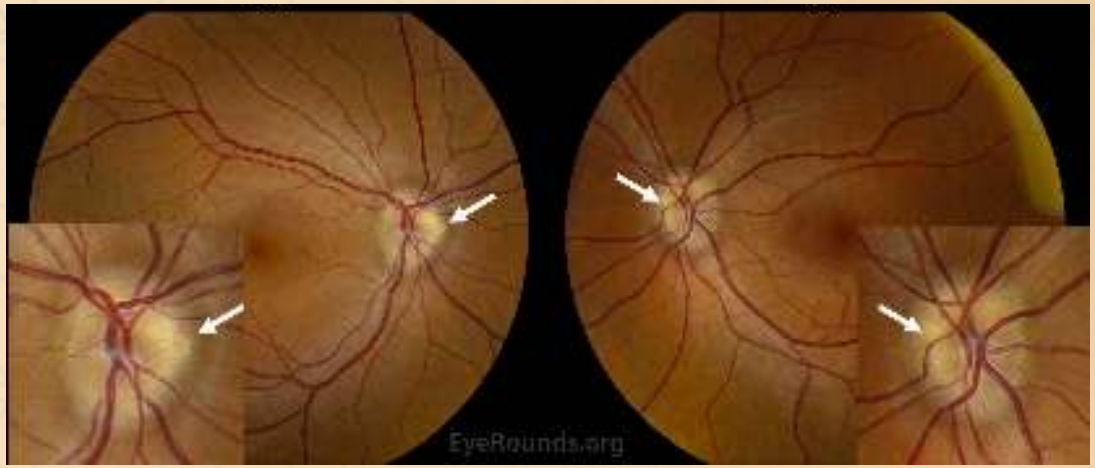
- **Tetracyclines** (incl. minocycline), nalidixic acid, sulphonamides, nitrofurantoin, penicillin
- **Vitamin A** / **retinoids**
- Growth hormone, thyroxine, levonorgestrel, anabolic steroids
- **Lithium**, ciclosporin, amiodarone, phenytoin
- Withdrawal from chronic steroids
- Endocrine: Addison disease, hypo/hyper-parathyroidism, hypo/hyper-thyroidism
- Refeeding in malnourished children, Behçet, Lyme (selected cases)

Paediatric ophthalmology assessment

Core objectives

- Confirm **true** papilloedema vs **pseudo-papilloedema**
- Quantify **visual risk** at baseline
- Create **reproducible metrics** for surveillance and treatment decisions (MDT communication)





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Source: OUH paediatric neurology guideline “IIH: investigation and management in children” (Aug 2018).

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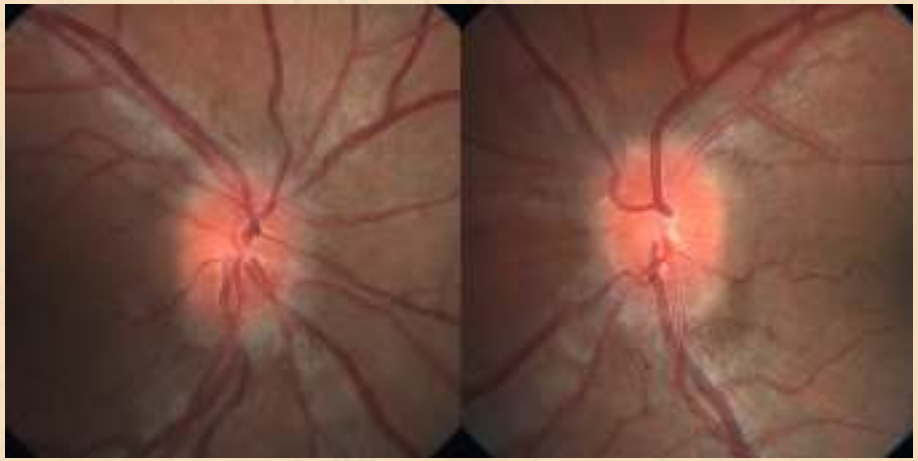
Clinical assessment (every visit)

- Visual **acuity**, **colour** vision
- Pupils (**RAPD**), ocular **motility** (CN VI palsy / diplopia)
- Dilated fundus exam: disc swelling, **haemorrhages**, macular oedema, optic neuropathy
- Document papilloedema **severity** (e.g. grade) and change over time



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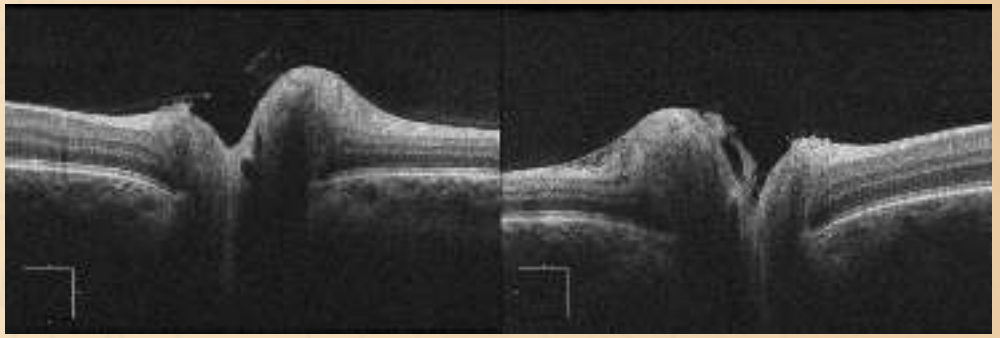
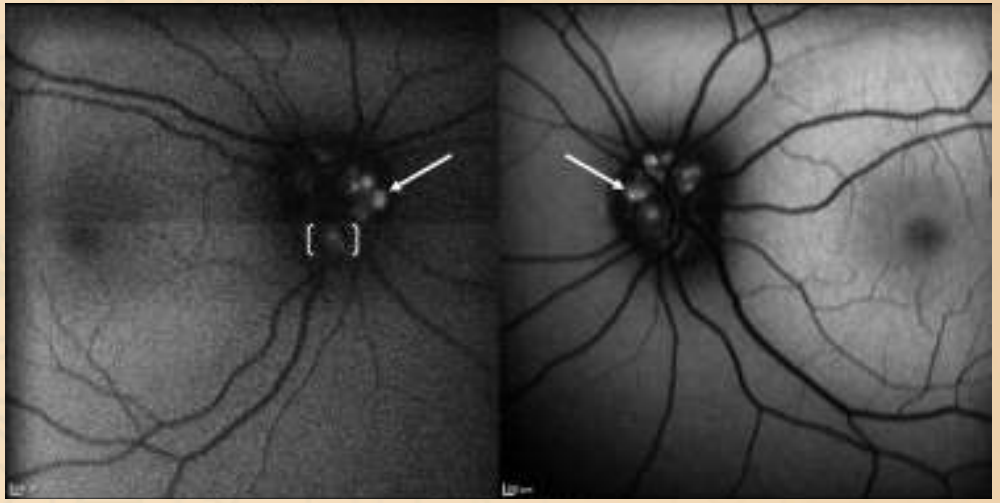
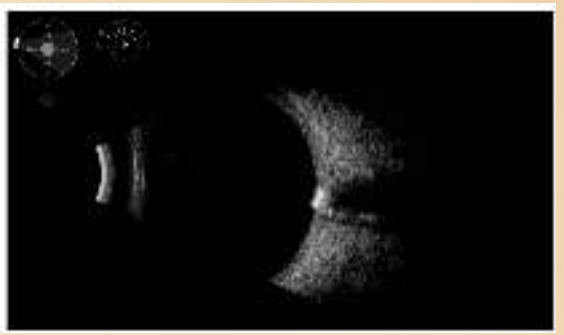
Objective testing & imaging

- **Visual fields** where cooperative- recommended in age> 7 years
- **Baseline OCT** (ONH + RNFL; macular GCL)
- Fundus **photography** for baseline + serial comparison
- Fundus **autofluorescence** ± **B-scan** ultrasound at baseline







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Follow-up & escalation

- Ophthalmology review typically **every 3–6 months** when stable
- **Urgent escalation** if: falling VA/colour vision, worsening VF, new RAPD, rapidly increasing swelling
- Severe papilloedema with threatened vision: consider emergency **neurosurgical intervention**
- Be explicit in **MDT handover**

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Source: GOSH paediatric neurology guideline “IIH: investigation and management in children” (Aug 2018).

Delphi consensus recommendations

- **Possible IIH without red flags**: hospital assessment within 2 weeks
- **Suspected IIH with normal vision**: **MRI + MRV** within 7 days
- **Suspected raised ICP** (early morning headache/vomiting/visual disturbance/focal neurology): **neuroimaging** within 24 hours (MRI/ MRV preferred; CT/ CTV if unavailable)
- **Baseline bloods**: TFT, Na/K/urea/creatinine, LFT, Ca/PO4/Mg, glucose, vitamin D, FBC; lipid profile if BMI>25
- **LP** for diagnosis unless contraindicated; in **acute visual loss** aim first **LP** within 48 hours
- Use **Friedman diagnostic criteria**; **MDT review** for atypical cases / younger children (must up to 10 years)

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Amin et al. Arch Dis Child (Delphi consensus; doi:10.1136/archdischild-2023-326545).

Treatment

- 1st line: **Acetazolamide** 15–25 mg kg^{-1} d^{-1} (max 100 mg kg^{-1} d^{-1}).
  - Relapse 26 % after stopping acetazolamide—taper slowly with repeated fields.
- 2nd line: **Topiramate** 1.5–3 mg kg^{-1} d^{-1}; caution in adolescent females (OCP interaction, teratogenic)
- Interventions (*less common*)
  - **Shunts** are often employed: shunt failure higher than adults
  - **Venous sinus stenting**: performed less commonly than shunting, no safety data in paediatric population
  - when vision acutely threatened, severe cases: **optic-nerve fenestration** (tolerated poorly, experienced surgeon)

Audit: aims and methods

Aim

Describe **real-world** management of suspected **paediatric IIH** against the local pathway and highlight practical challenges.

Data captured

- Symptoms + demographics
- Ophthalmic outcomes: VA, Frisén grade, OCT RNFL, visual fields
- Imaging findings + time to imaging
- LP opening pressure + CSF results
- Treatment and time to medication

Design

- **Retrospective** service evaluation
- Data capture from Nov 2022 to present
- Inclusion:
  - <18 years of age
  - clinician-diagnosed or treated as IIH
  - Plus ≥2 of: papilloedema, raised LP OP, normal CSF, neuroimaging excluding secondary cause
- Subgroups: "**definite**" vs "**probable**" (missing one key element, often LP/CSF detail)

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Demographics and symptoms

Demographics		
N	N	12
♀	Sex	67% female (8/12)
A	Age	Median 13 years (range 5–17)

Symptoms recorded		
H	Headache	12/12 (100%)
N	Nausea	3/12 (25%)
V	Vomiting	1/12 (8%)
D	Dizziness	1/12 (8%)

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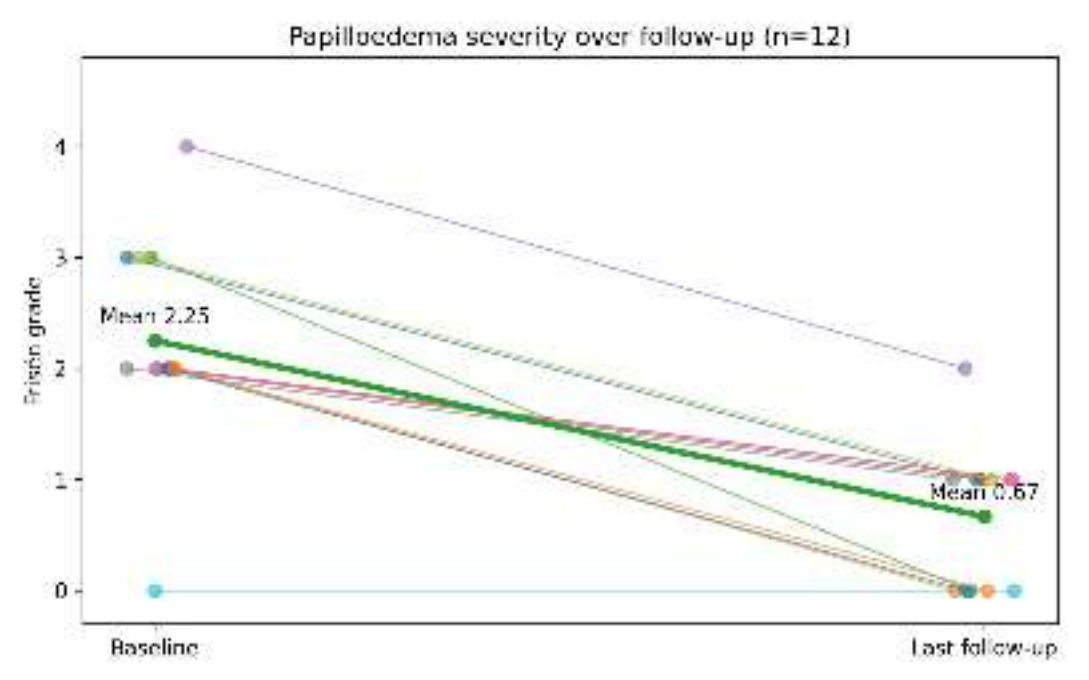
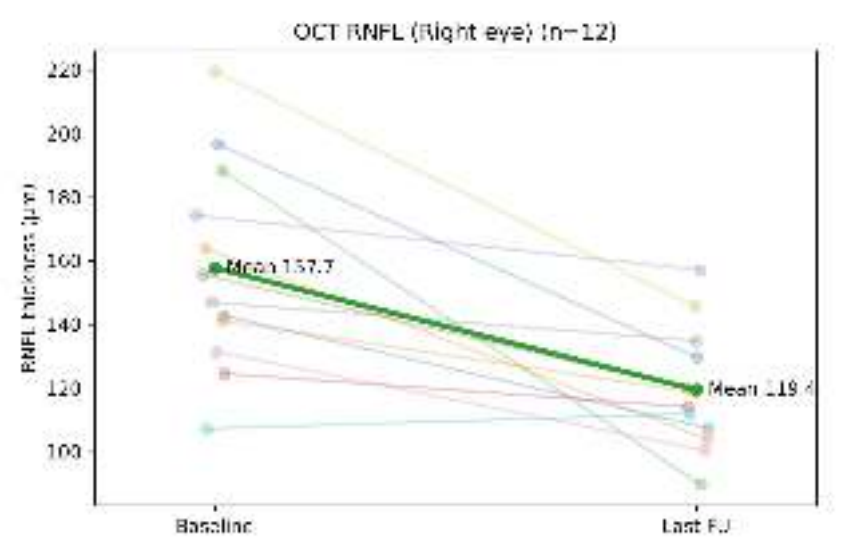
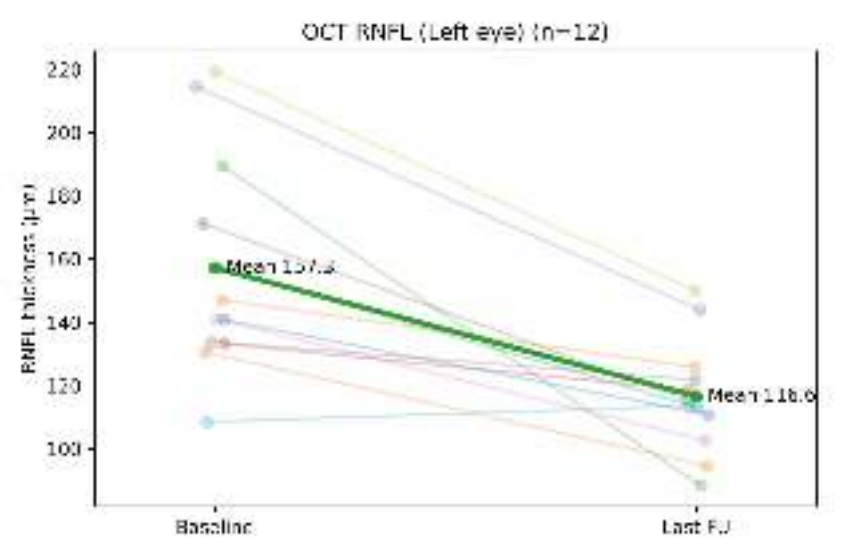
Papilloedema



OCT RNFL





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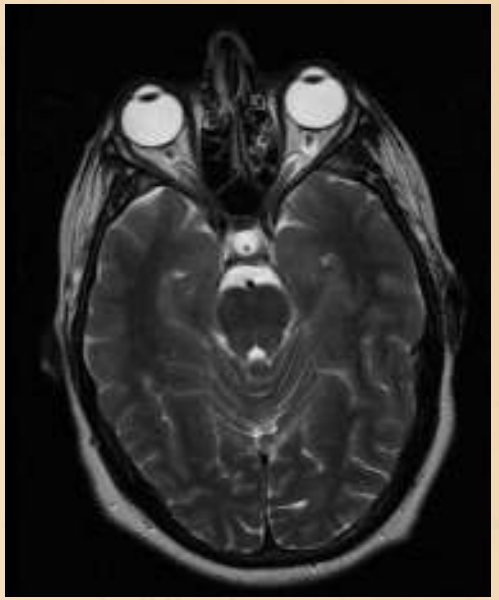
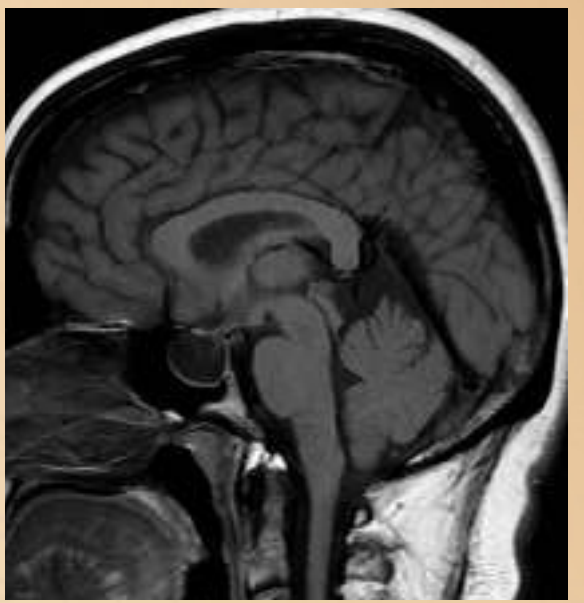
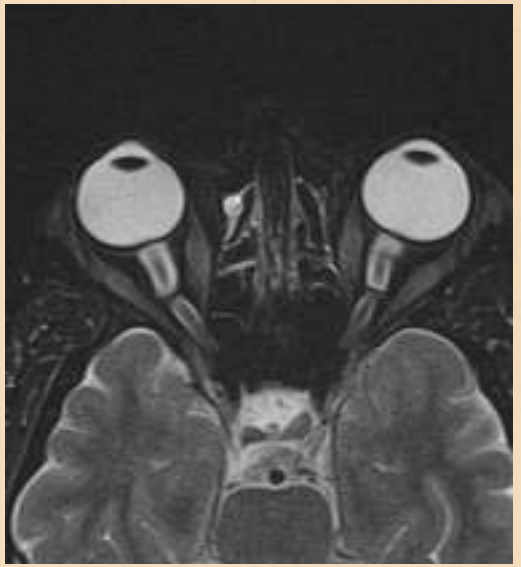
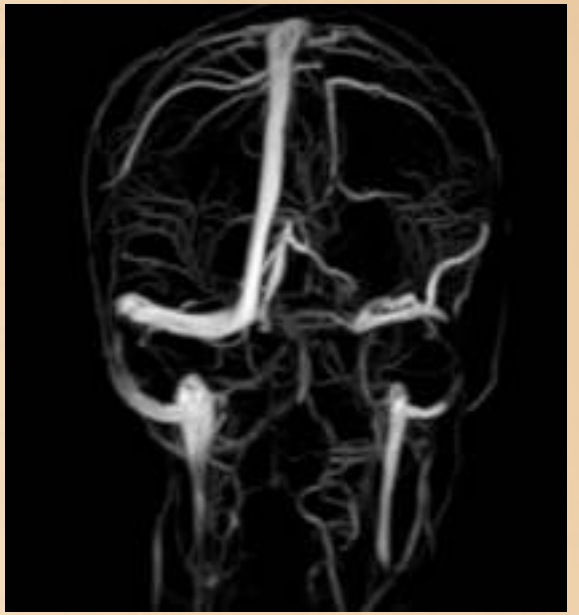
Neuroimaging

- **IIH features** (soft signs) : 6/12 (50%)
- Normal: 4/12 (33%)
- Done elsewhere: 2/12 (17%)
- Referral → imaging time: median delay = **4 days** (range 0–30)









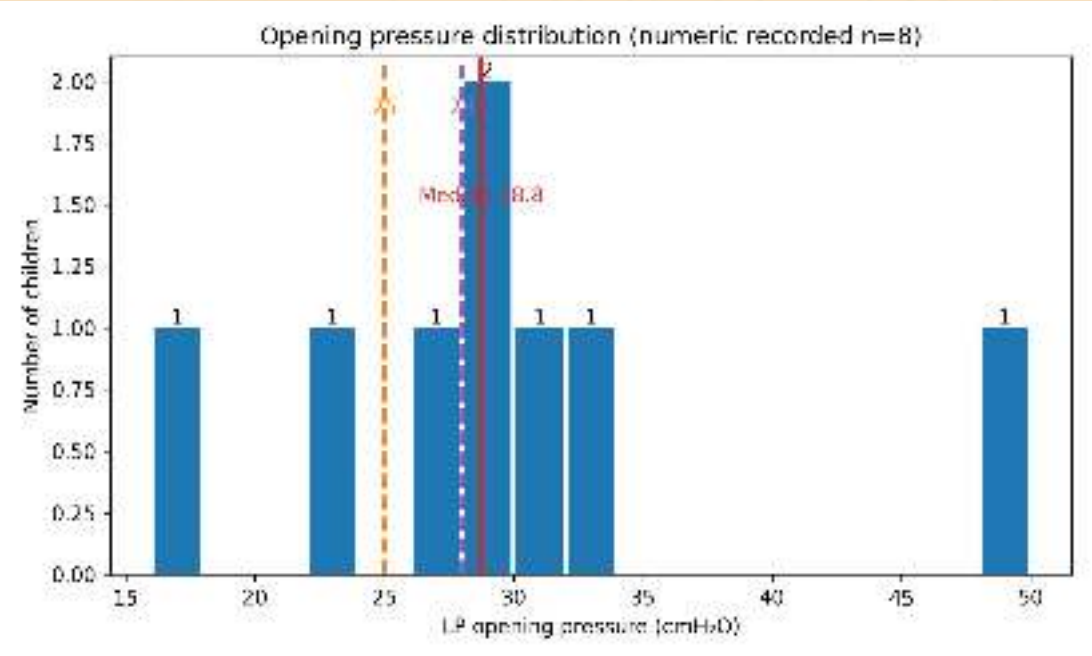
Visual acuity

- VA was **preserved**
- 11/12 eyes were 6/6 or better at last follow-up
- one eye was 6/9

Visual fields

- VF MD recorded: **7/12** (58%)
- Unreliable: 1/12 (8%)
- Not done: 4/12 (33%)
- Mean MD: RE **–1.86 dB**, LE **–1.62 dB**

Lumbar puncture



- Numeric OP recorded: 8/12 (67%)
- LP failed attempts (multiple attempts, stopped): 2/12
- LP done elsewhere: 2/12
- Median OP: **28.75 cmH_2O** (range 17–49)
- ≥25 cmH_2O: 6/8 (75%)
- ≥28 cmH_2O: 5/8 (63%)
- CSF documented as **normal**: 8/12 (67%), **100%** of those performed

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Treatment

- **Acetazolamide**: 10/12 (83%)
- **Topiramate**: 5/12 (42%)
- **Propranolol**: 1/12 (likely headache phenotype management)
- Procedures: 0/12
- Timeline to meds
  - Documented: 6/12 (50%)
  - Median delay: **15 days** (range 7–30)

Follow-up interval

- Median: **3.18 months** (range 2.91–6.00)

Challenges

1) Diagnosis vs “probable” IIH

LP/CSF data may be **missing** (technical difficulty, GA, timing). The pathway still needs a safe route for “probable” IIH with clear safety-nets.

2) Lumbar puncture realities

Opening pressure depends on position/sedation; attempts may fail. The fix is not “do more LPs” — it’s making a decision based on **available evidence** + **escalation thresholds**.

3) Measuring function in children

Perimetry can be **unreliable** in younger children. We need explicit alternatives: **VA** + **Frisén** + **serial OCT** trend + **symptom** trajectory.

4) Long-term management

Headache phenotype, **weight** management, **adherence**, and **follow-up** coordination often drive outcomes as much as acetazolamide dosing.

Thank you!

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