Practical Post-Treatment Considerations

4th Annual CSF leak symposium

Cedars Sinai Medical Center

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October 2, 2021

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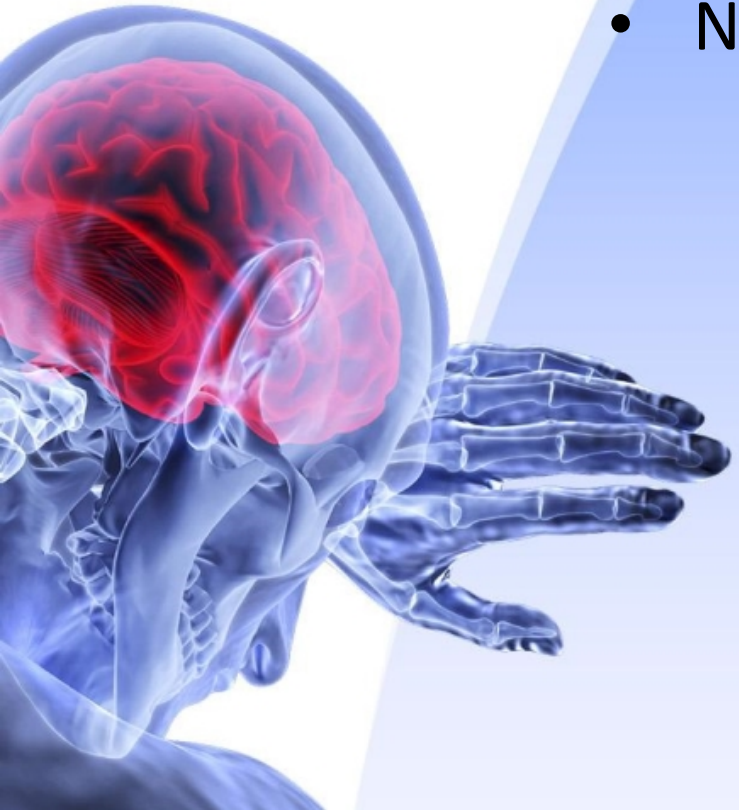
Disclosures

- None



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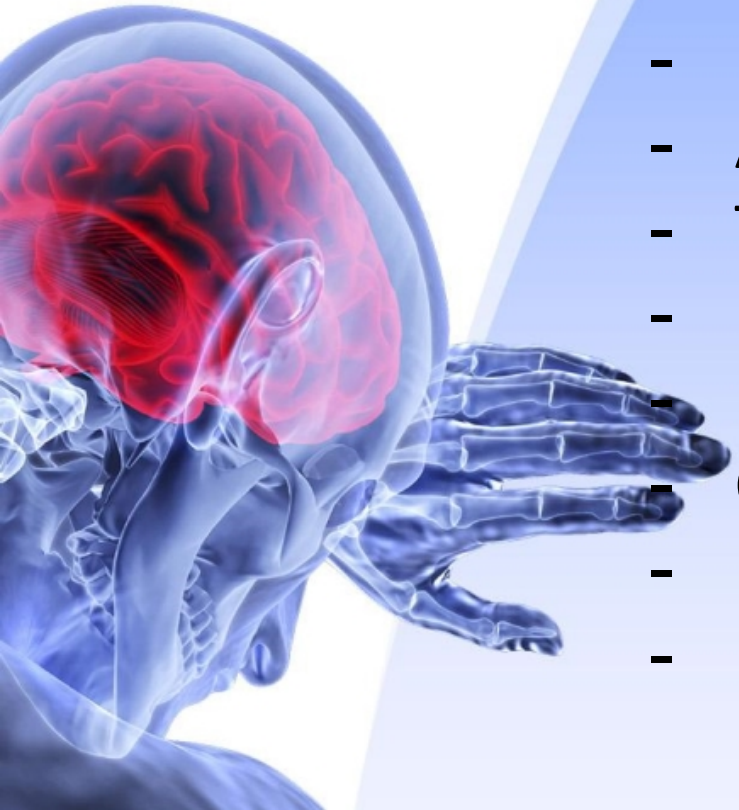
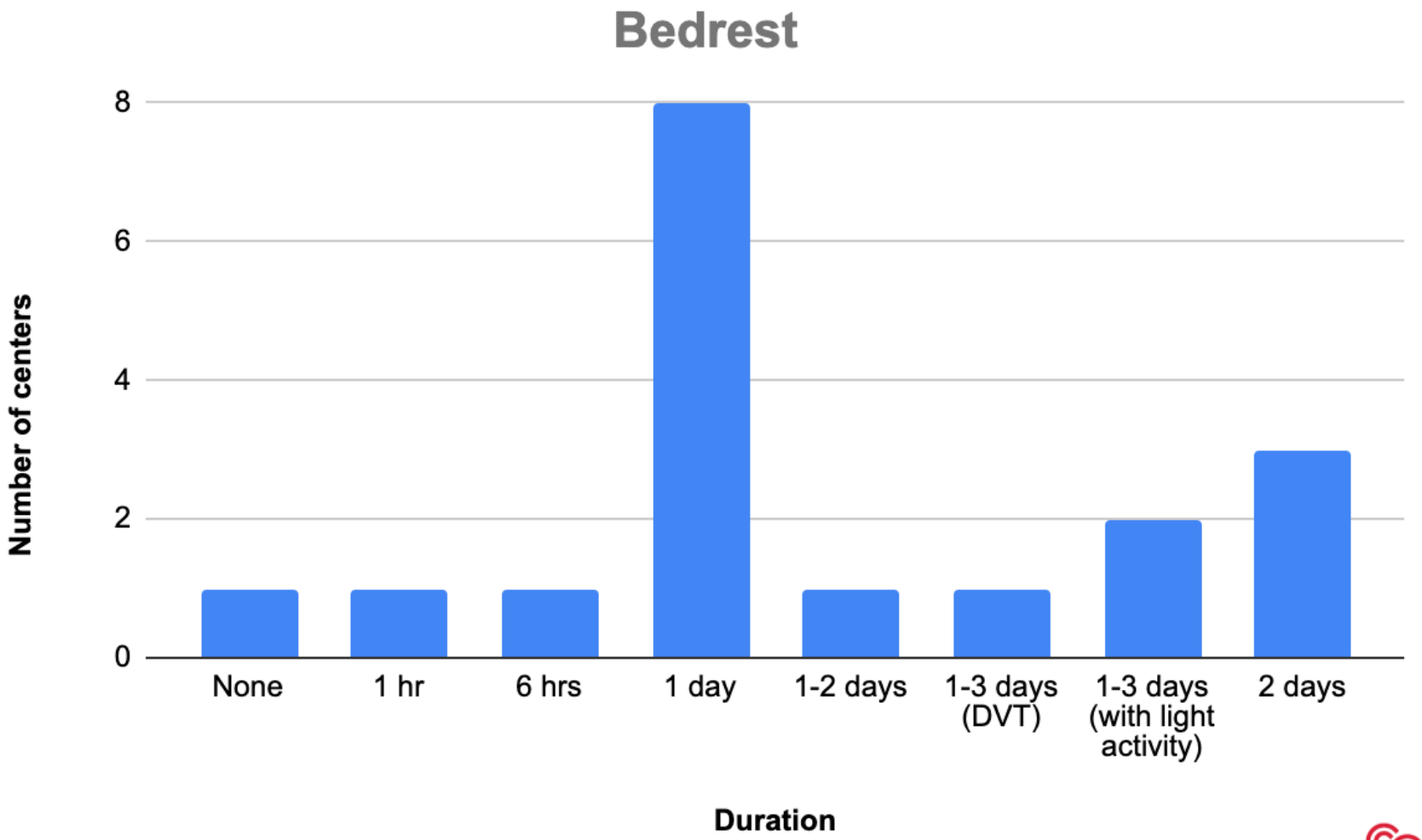


Post EBP Management Survey

- 21 centers responded to the survey
- Limitation of activity levels
- Analgesic management
- Travel restrictions
- Prevention and management of cough
- Nausea/Vomiting
- Constipation
- Rebound Intracranial Hypertension
- Managing expectations & Success of Tx



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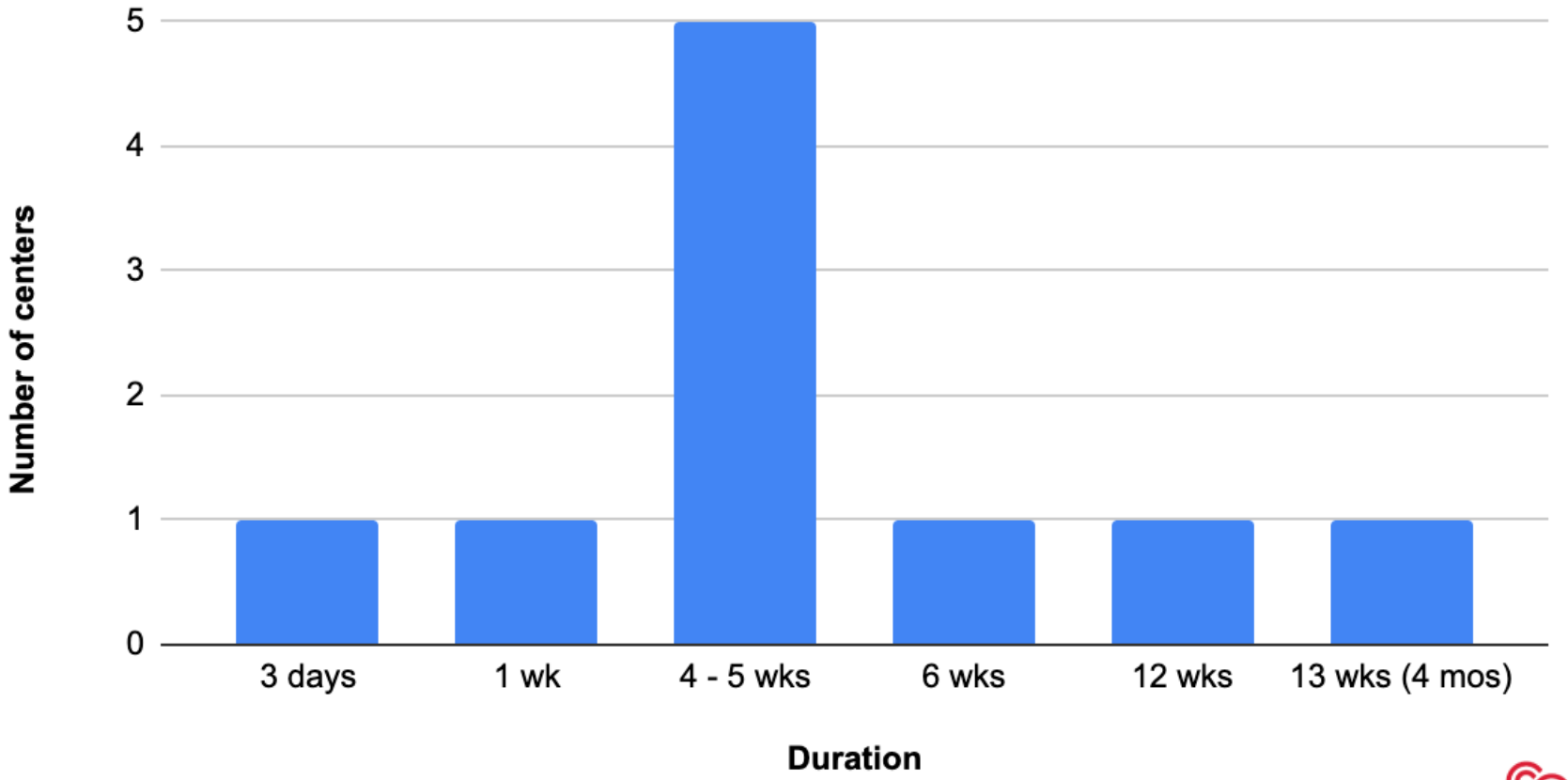
Light activity or avoidance of specific activities (besides the BLT category)



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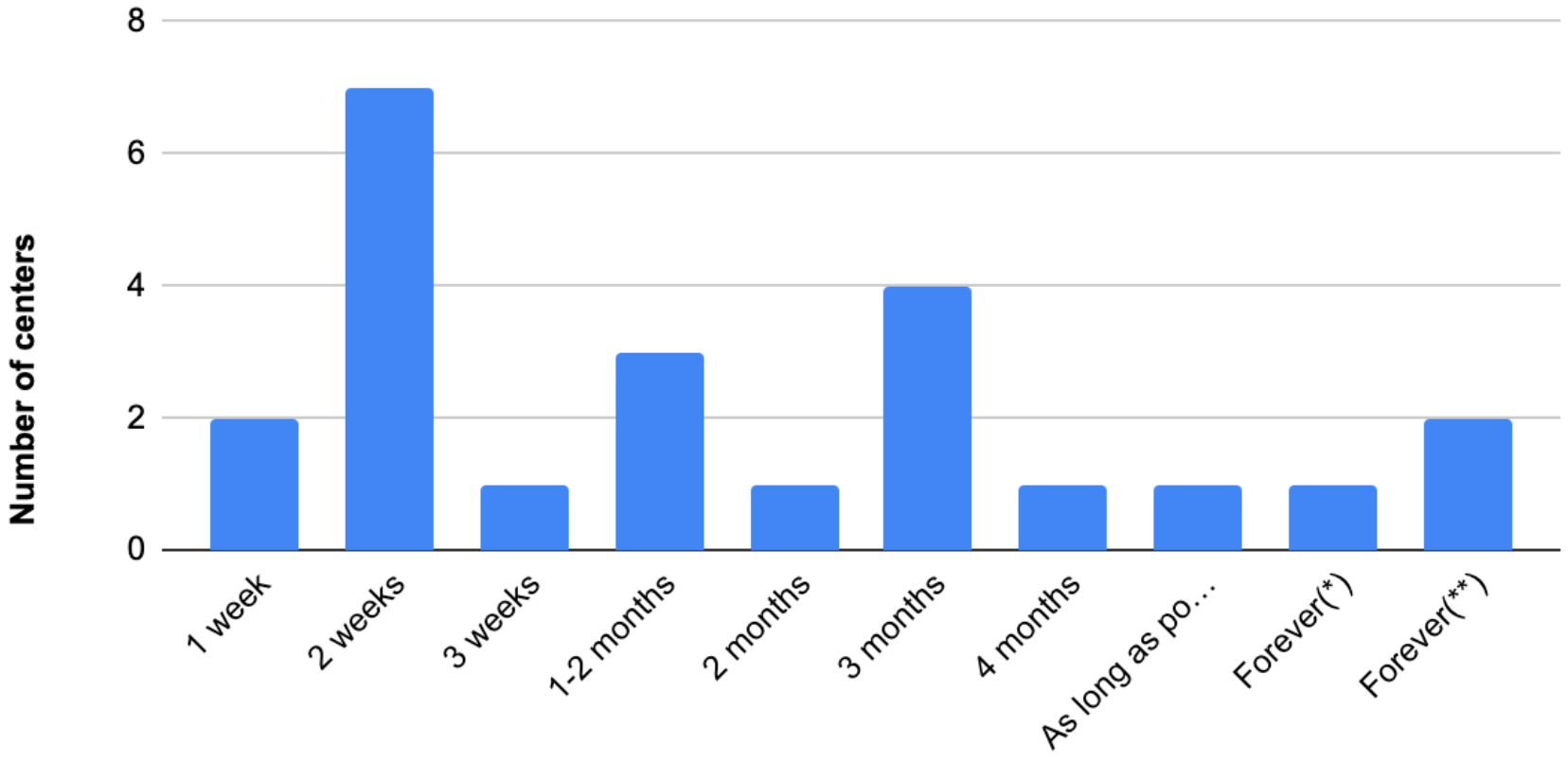
No BLT: Duration



Duration (*)=Joint Hypermobility; (**)=No jumping, No chiropractic manipulations

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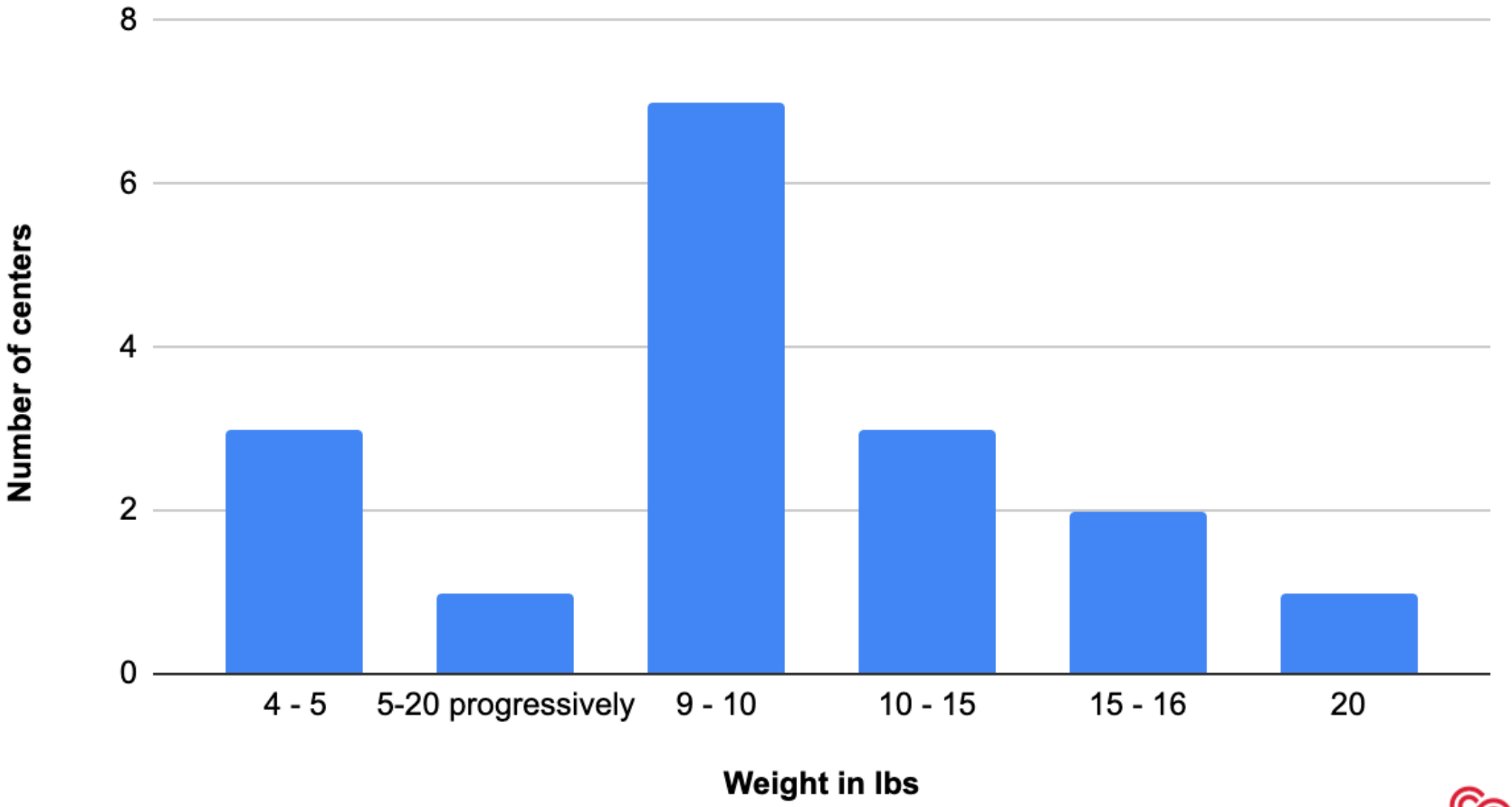
Limit on total weight to be lifted (lbs)



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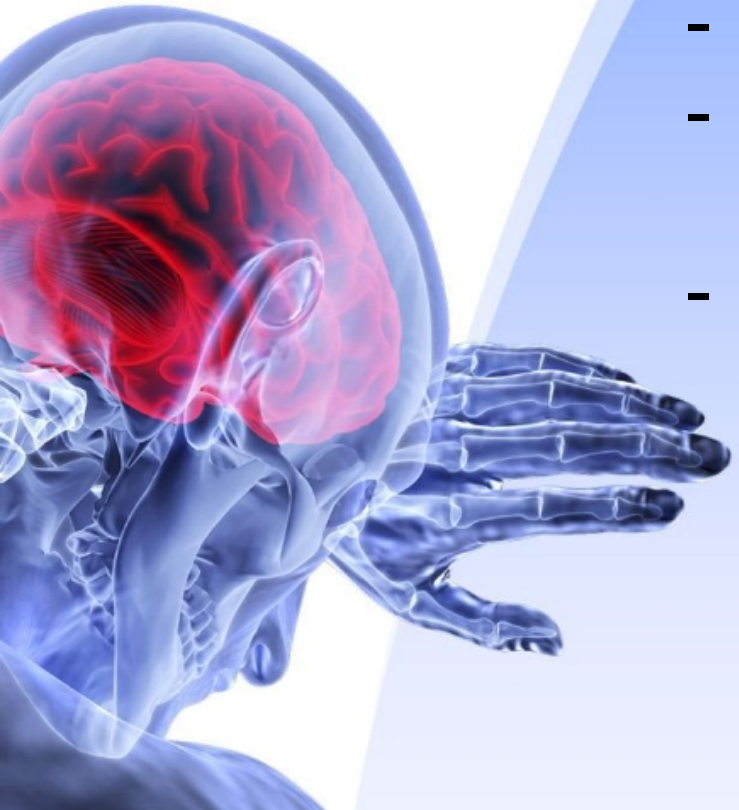
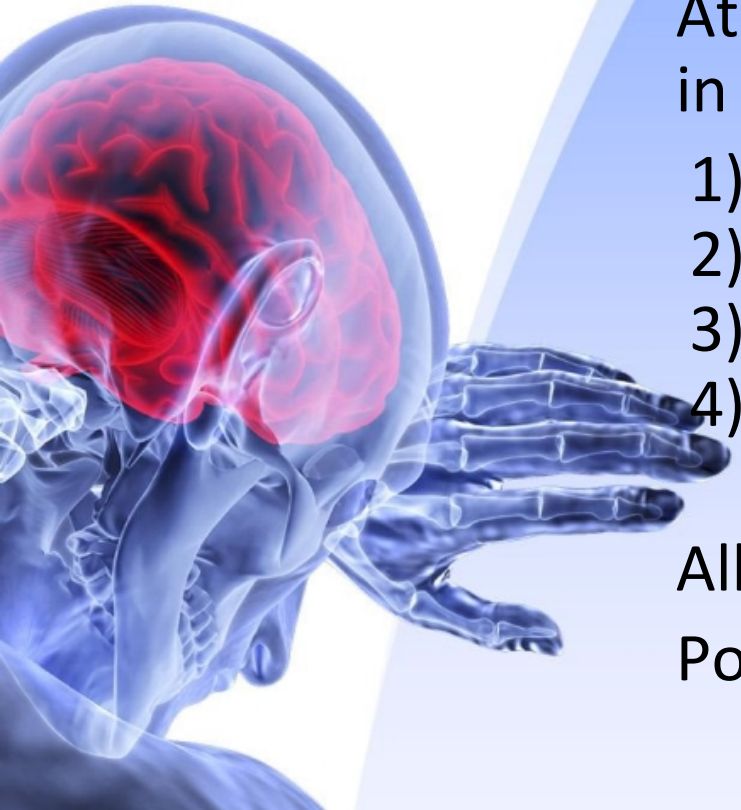
Sexual Activity Restrictions

- Avoid sexual activity x 4 weeks (1 ctr)
- Woman-on-top/Man-on-bottom (2 ctr)
- SIH patient on bottom x 4 weeks (1 ctr)



Post-EBP Analgesia



At Cedars-Sinai: Intense multimodal orders in PACU:

1) Acetaminophen 1g PO q4h x 2 doses
2) Gabapentin 300 mg PO q4h x 2 doses
3) Tramadol 50 mg PO q4h x 2 doses
4) Methocarbamol 500mg PO q4h x 2 doses

All meds to be given SIMULTANEOUSLY

Post-discharge: PRN acetaminophen only

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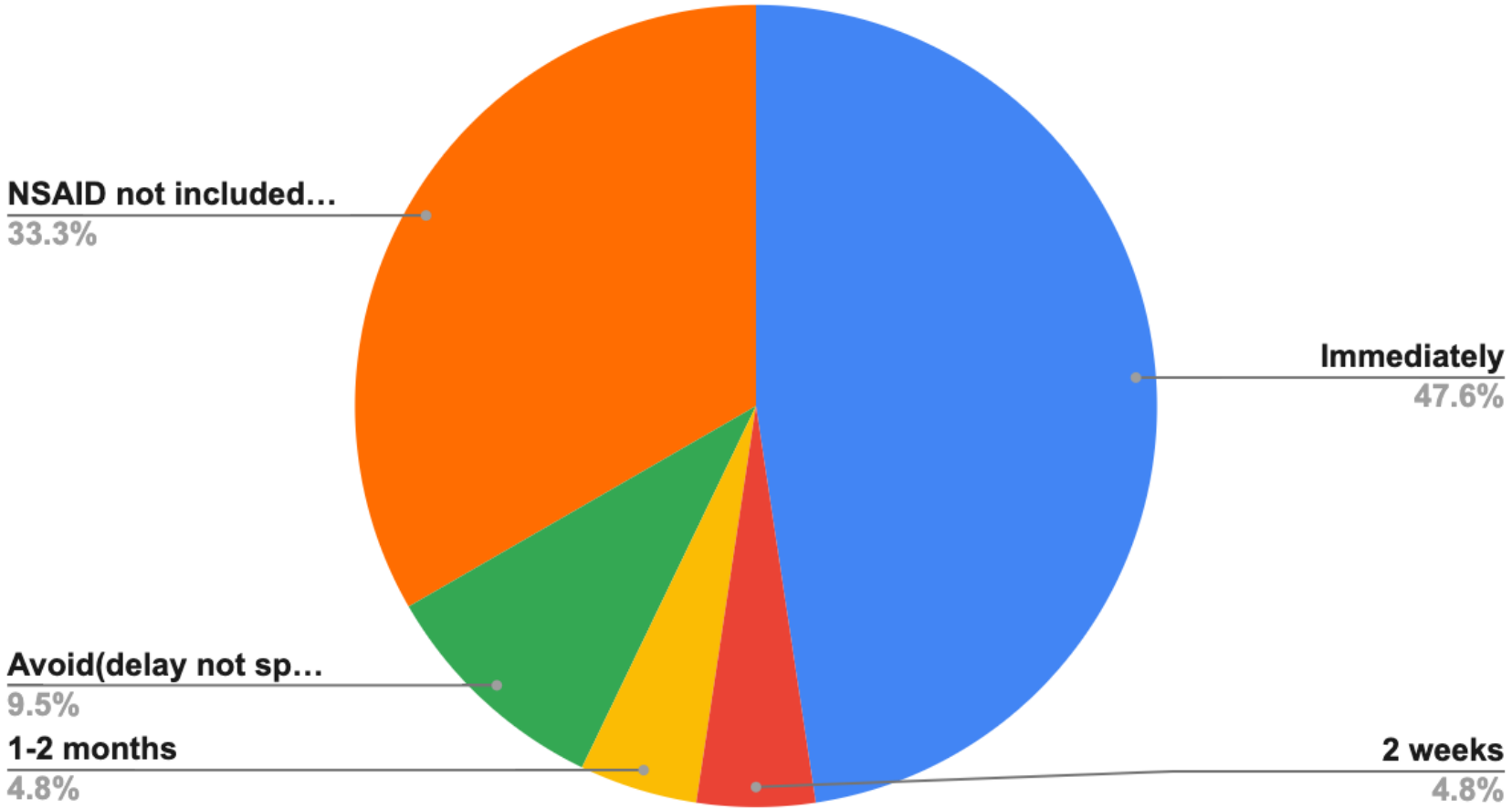
When can you start NSAIDs



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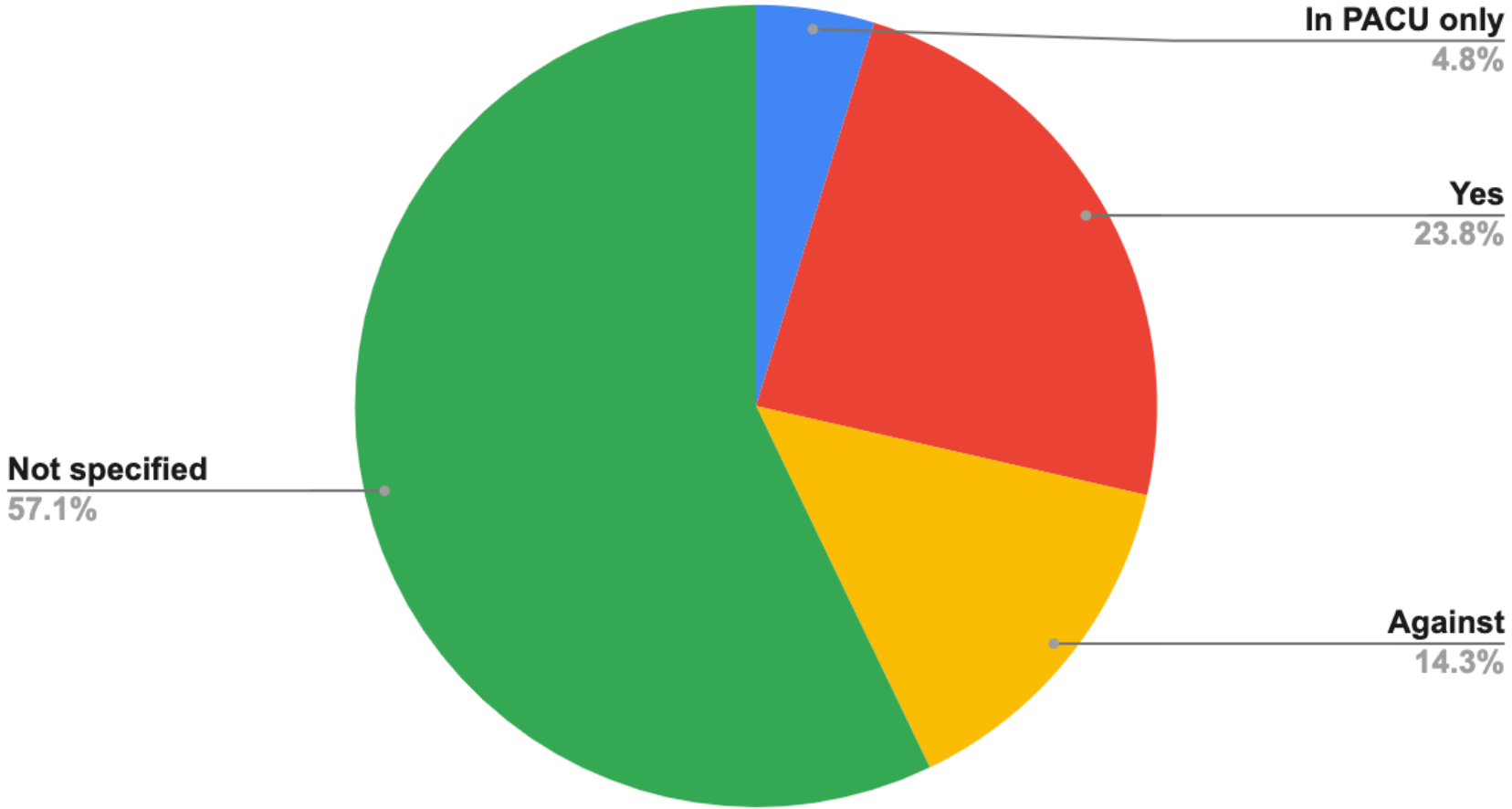
Gabapentin or Pregabalin



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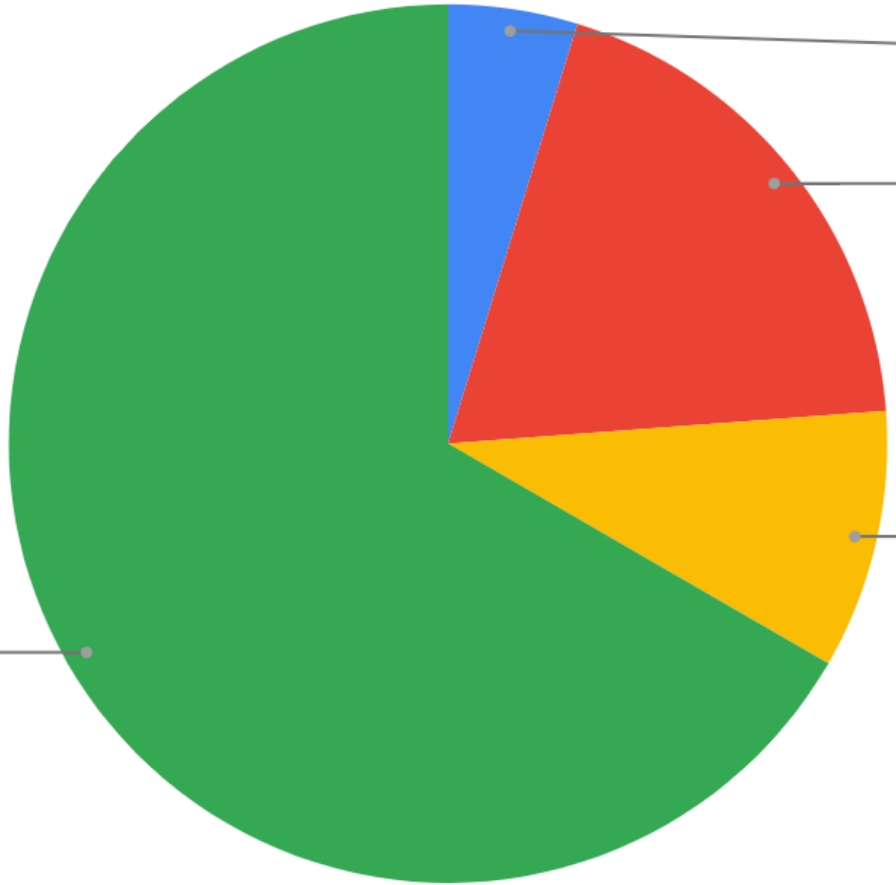
Muscle relaxants



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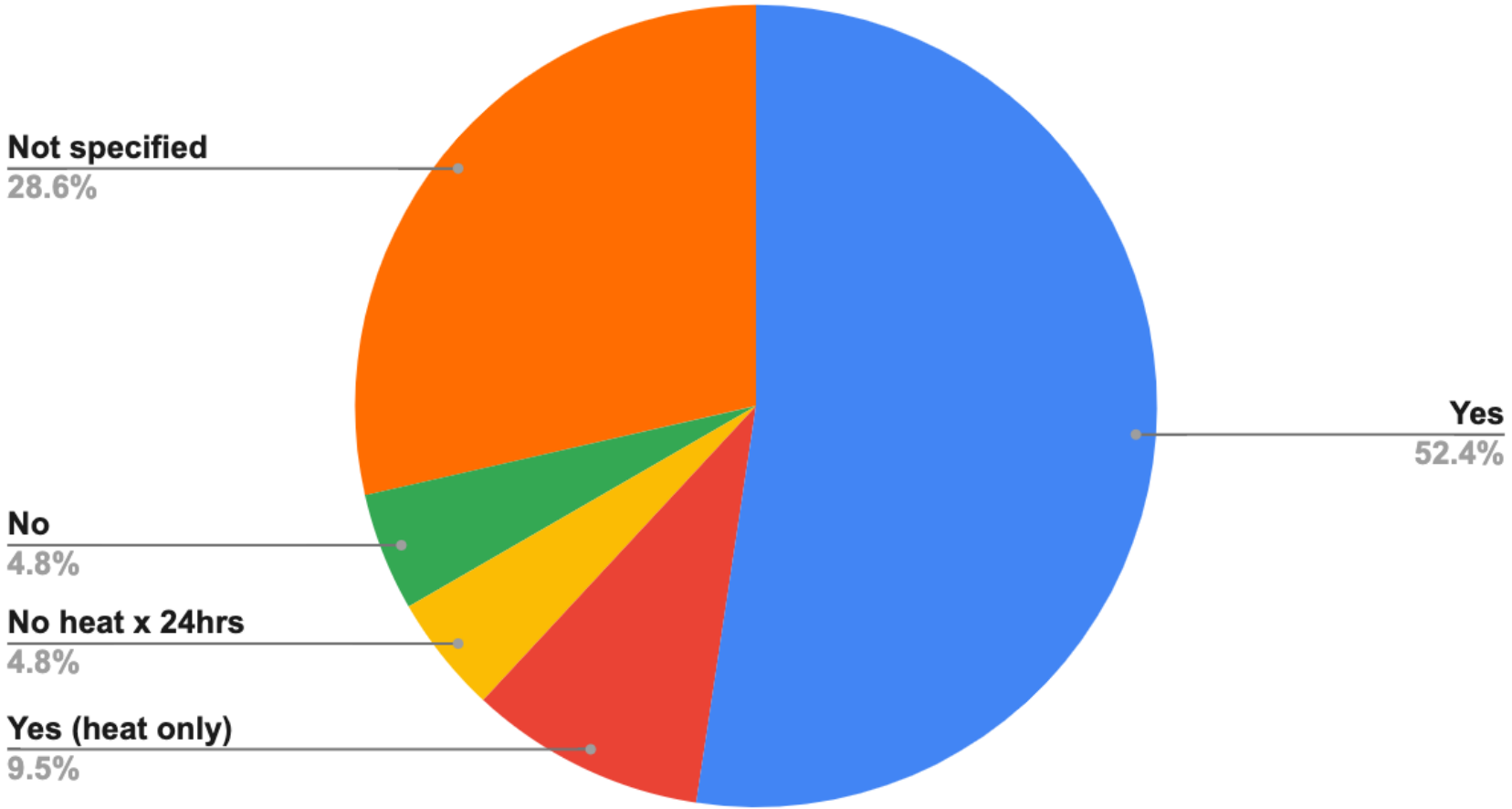
Heat/Cold

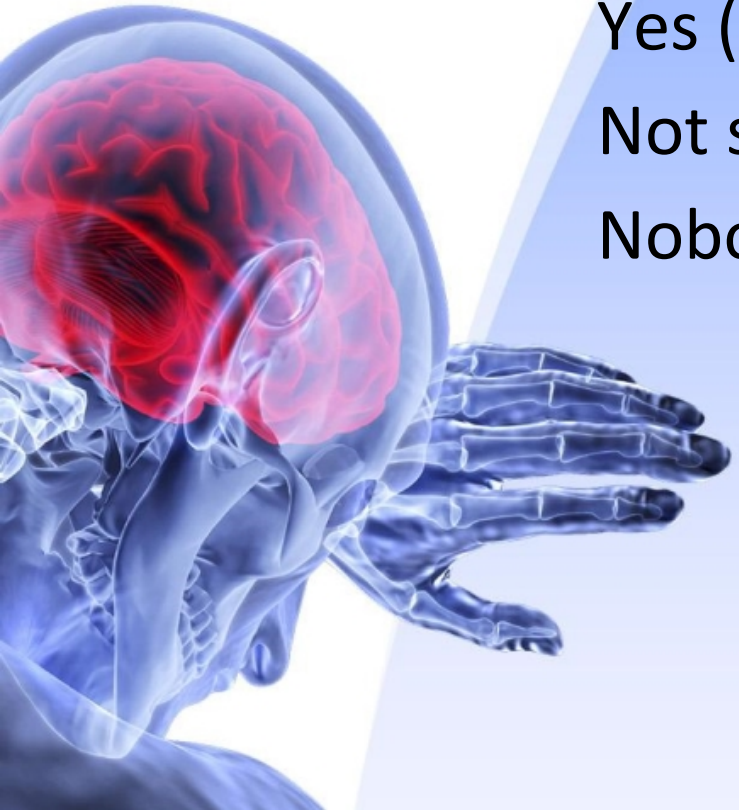


Acetaminophen

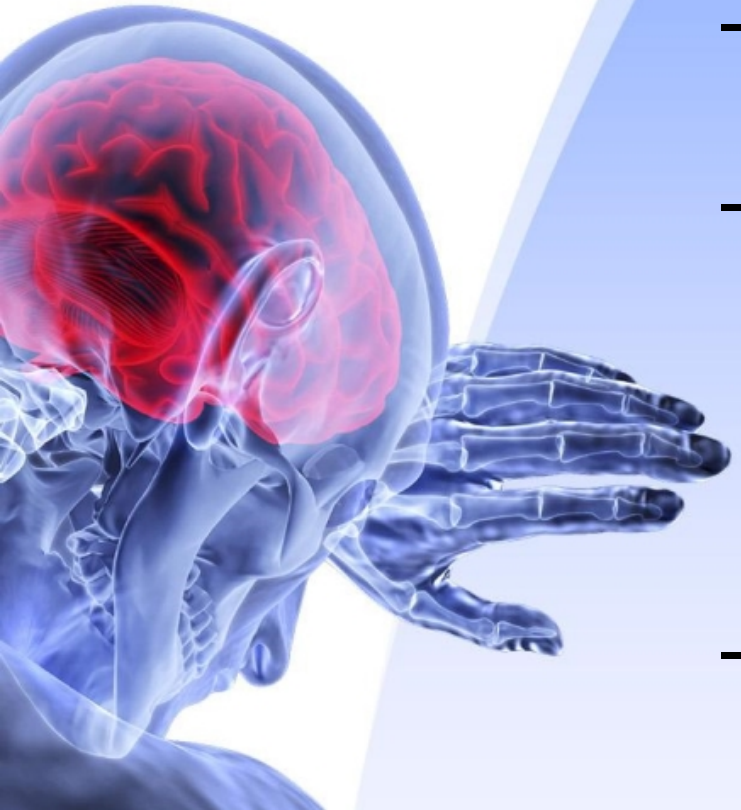
Yes (11 centers) 58%

Not specified (8 centers) 42%

Nobody was against it



Limitations of the Results



- Lack of independence (Centers communicate with each other)
- No stratification between
  - “High volume” EBPs (radicular pain)
  - Standard volume EBPs
  - Targeted EBPs
- Loss of nuances when quantifying results

Travel Post-Treatment

- Total of **21** CSF leak centers surveyed domestically (including Cedars Sinai) and internationally
  - All centers agree that both driving or flying are safe modes of transportation post treatment
    - One ctr in Germany mentioned traveling by train

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Travel Post-Treatment

- **Short distances (1-2 hours)**
  - No specific recommendations after mandatory bedrest: **14/21**
    - 1/14 ctr admit patients on PPD0 (Germany)
    - 3/14 centers recommended no driving the day of the procedure (including Cedars)

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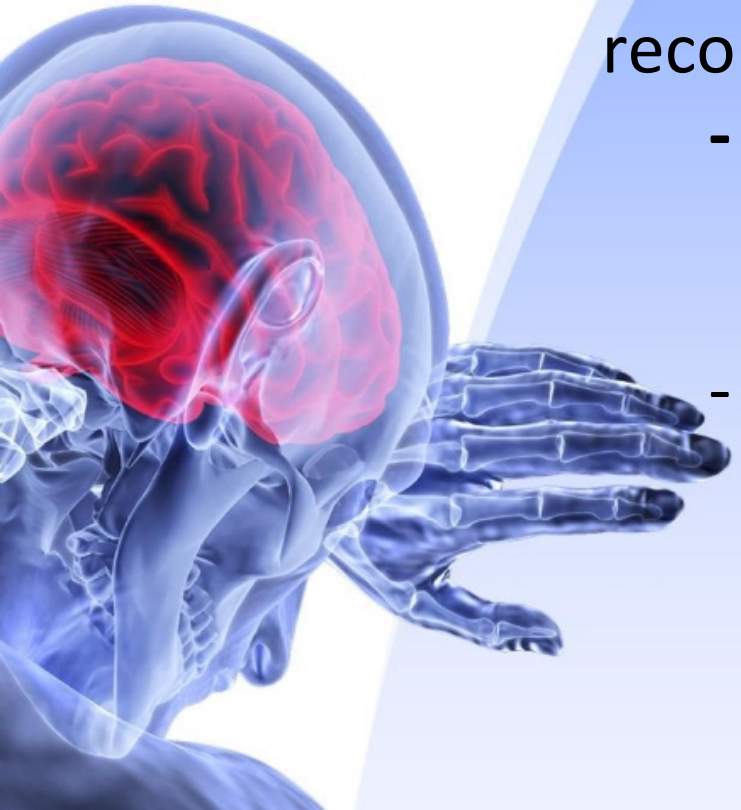
Travel Post-Treatment

- Lying recumbent or flat when driving for **short distances**: **7/21**
  - Avoiding bumpy car rides: **4/7**
    - **1/4** Avoiding bumpy car rides for a total of 15 days (Italy)
  - One center from the UK report patients are unable to totally lie flat since seatbelts are necessary
  - One center recommended a foam mattress as a shock absorber
  - Wheelchair from hospital bed to the car then climb slowly into passengers seat and recline the chair to 45 degrees until they get home, then onto the couch, bed, or lazy-boy recliner

Travel Post-Treatment

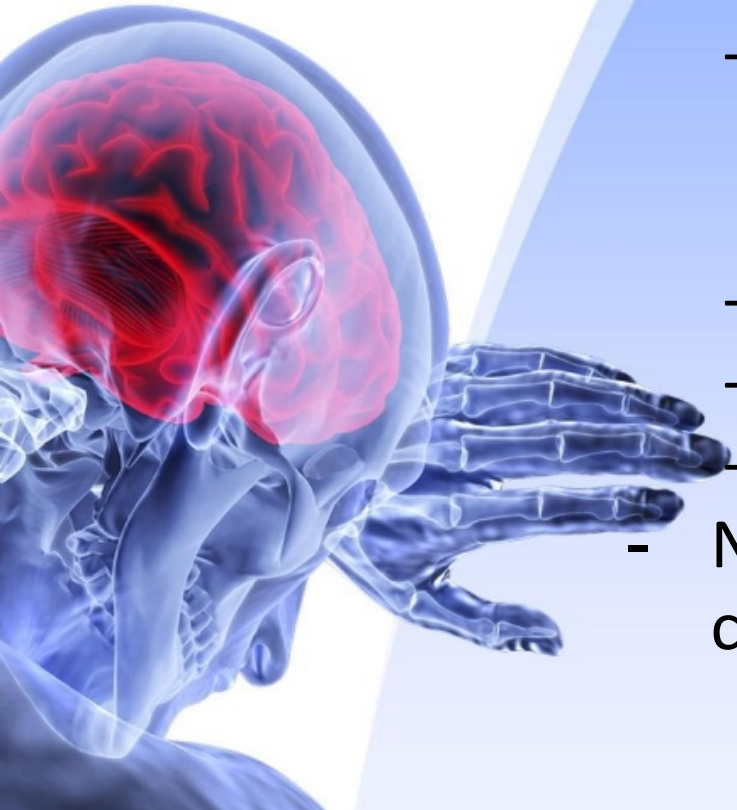
- **Long distances (>2 hours)**
  - No recommendations after mandatory bedrest: **9/21**
    - **2/9** centers only have local patients (UK)
  - **1/21** centers recommend no air travel for 1 month (Italy)
  - Stay at a local hotel for PPD0 - PPD1: **7/21**
  - Stay at a local hotel for PPD2 or longer: **4/21**

Prevention & Management of Cough



- All **21** CSF leak centers surveyed do not recommend preventative treatments
  - **6/21** centers mentioned that problems with coughing is uncommon (2/6 are international)
  - Consider preventative treatment for patients with history of asthma, COPD, bronchitis, or medications that can cause cough

Prevention & Management of Cough



- Management of cough as needed: **8/21**
  - OTC cough suppressants or antitussive agents PRN (i.e., cough lozenges or dextromethorphan): **5/21**
  - codeine PRN: **1/21**
  - tessalon Perles PRN: **1/21**
  - levodropropizine PRN: **1/21**
- No specific recommendations to manage cough: **13/21**

Prevention & Management of Nausea/Vomiting

- Total of **21** CSF leak centers surveyed domestically (including Cedars Sinai) and internationally
  - **2/21** centers find that nausea and vomiting are not issues in their practice and had no specific recommendations (both are international)

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Prevention & Management of Nausea/Vomiting

- **1/21** centers recommend both preventative and PRN treatment
  - Every patient receives IV ondansetron (Zofran) and diphenhydramine (Benadryl) prior to treatment and every patient receives a Rx for ondansetron ODT (Zofran) and promethazine (Phenergan) suppository post treatment

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Prevention & Management of Nausea/Vomiting

- **19/21** centers treat nausea and vomiting as needed
  - **Antiemetic therapy**
    - Ondansetron 4-8 mg: **13/19**
      - One center is cautious with prescription given that ondansetron can induce constipation
      - One center advises patients that it can reverse the effect of Tramadol at the 5HT3 receptor
    - Rare prescription from one center (Germany)

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Prevention & Management of Nausea/Vomiting

- **19/21** centers treat nausea and vomiting as needed
  - Ginger tea or food (no supplements due to anti-platelet effects)**: 1/19**
  - cyclizine/metoclopramide(Reglan) as needed: **1/19**
  - metoclopramide (Reglan) as needed: **1/19**
  - prochlorperazine/domperidone as needed: **1/19**
  - Hydration: **1/19**
  - Admission to the hospital: **1/19**

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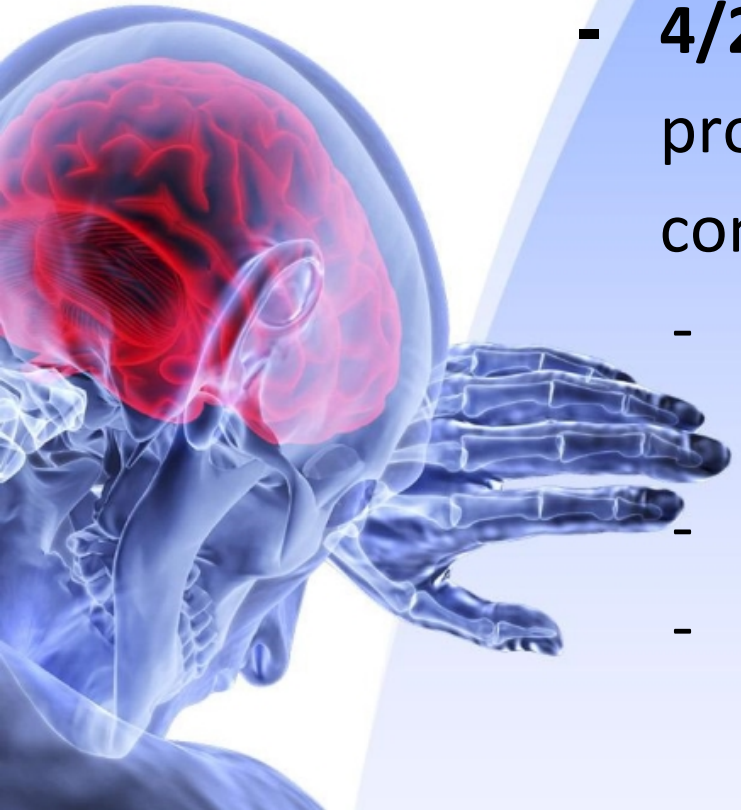
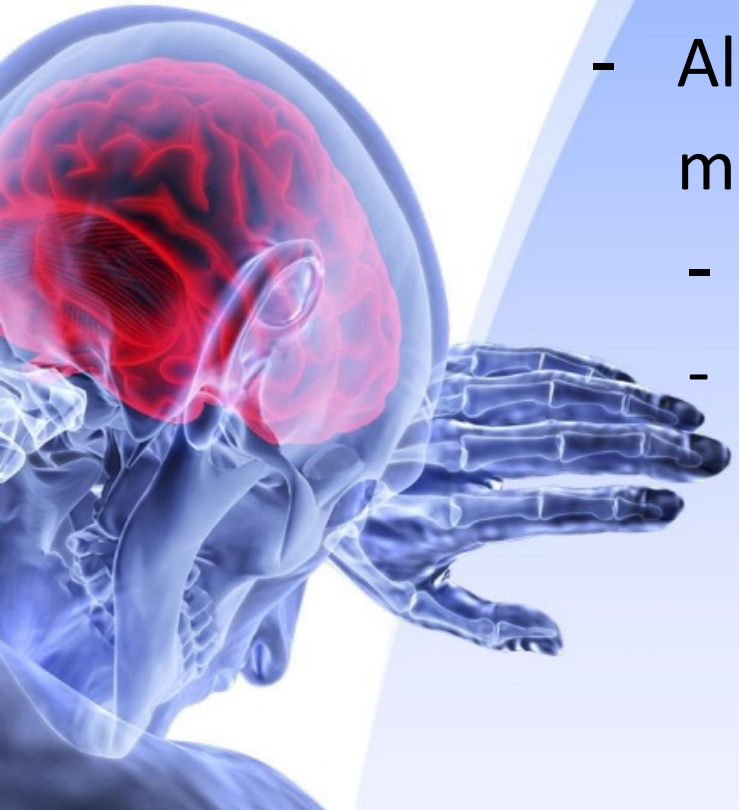
Prevention & Management of Constipation



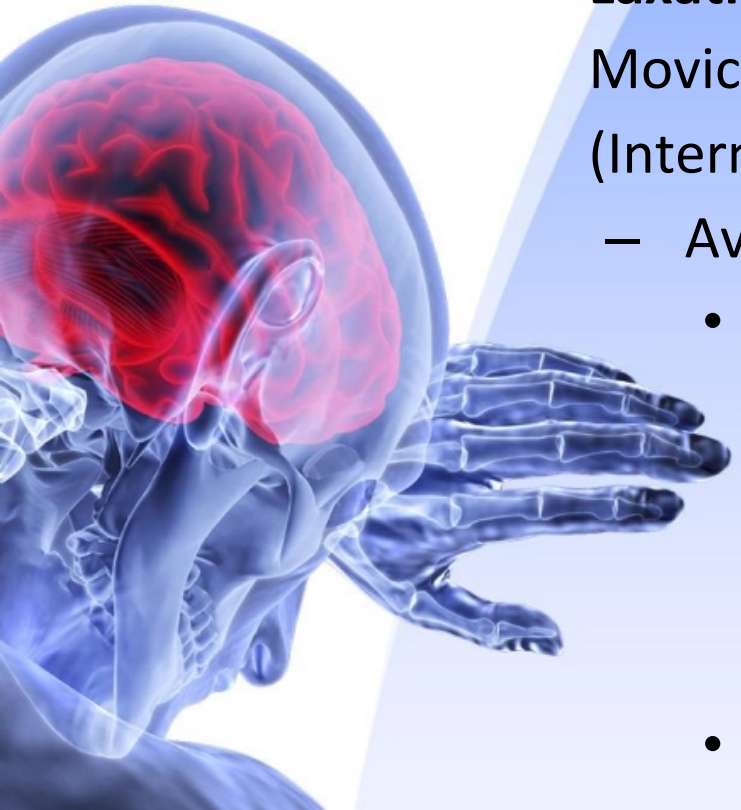
- **4/21** centers recommend preventive and prophylactic treatment, especially if constipation is a known issue
  - Daily polyethylene glycol (Miralax): **2/4**
  - Docusate sodium (Colace): **1/4**
  - Senna/Colace/Miralax if prone to constipation for 4 weeks: **1/4**

Prevention & Management of Constipation



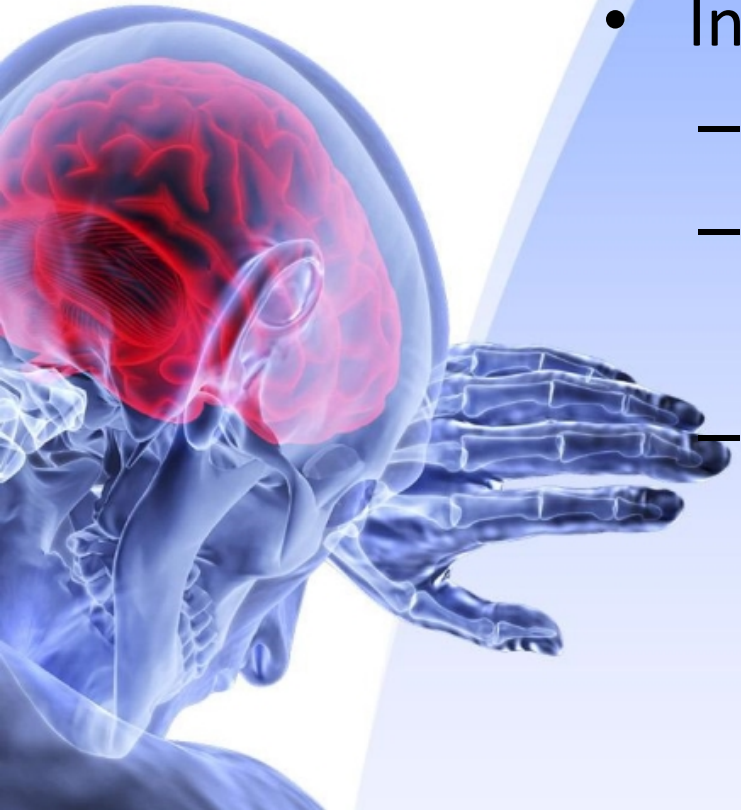
- All **21** CSF leak centers recommend management of constipation as needed
  - Not a common issue: **1/21** (Taiwan)
  - No specific recommendations: **3/21**

Prevention & Management of Constipation



- **Laxatives** particularly Miralax, Mineral Oil, Macrogol, Movicol, psyllium fiber (Metamucil), Lactulose (International- 3/17): **17/21**
  - Avoid laxatives than can cause cramping: **2/17**
    - bisacodyl (Dulcolax), senna or enemas to be avoided (although one center uses Dulcolax as 2nd line treatment, another center recommends enemas if needed, and another center recommends senna)
    - Colace, magnesium/milk of magnesia/senna

Prevention & Management of Constipation



- In addition to laxatives:
  - Adequate hydration: **1/21**
  - Avoid opioids unless patient is having severe pain: **3/21**
  - Diet rich in dietary fiber: **1/21**

Rebound Intracranial Hypertension

- Total of **21** CSF leak centers surveyed domestically (including Cedars Sinai) and internationally
  - **2/21** centers consider prophylactic treatment
    - Acetazolamide (Diamox) BID for prophylaxis following CSF venous fistula glue (Mamlouk 2021)
    - Preemptively start all patients on Diamox BID

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Rebound Intracranial Hypertension

- **6/21** centers recommend management of RIH based on severity of symptoms or treat conservatively
  - Tincture of time, unless severe, and reassurance that most cases are transient.
  - Be sure that the patient does not have another cause of different head pain, such as cerebral venous sinus thrombosis
  - One international CSF leak center finds that most of their patients have mild symptoms and respond to acetaminophen and occasionally NSAIDs

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Rebound Intracranial Hypertension

- Elevation of head of bed or sleep on extra pillows: 4/21
- Salt/caffeine restriction: 3/21
  - Reduce hydration to pre-CSF leak levels
  - Foods with carotenoids do NOT need to be restricted – this is a resistant and pervasive myth.
- Dandelion tea/capsules: 4/21
  - Recommend LEAVES, not the roots. Dried leaves are easy to locate online (Mountain Rose herbs is a good source). The LEAVES have some demonstrable diuretic effect, but no data specific to RIH.

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Rebound Intracranial Hypertension

- If medications are warranted for moderate to severe symptoms, **19/21** of the centers recommend **carbonic anhydrase inhibitors as 1st line treatment**:
  - **acetazolamide** (Diamox) dose varies by practice:
    - 125 mg QHS or BID, titrate as needed
    - 500 mg BID or TID, titrate as needed
    - 250 mg TID & acetaminophen 1000 mg BID (Italy)

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Rebound Intracranial Hypertension

- 250 mg BID or TID, titrate as needed
  - Start no sooner than PPD1 with option to increase both doses by 250 mg every other day to max 1000 mg BID
- Start those with high pre-test probability (papilledema in the past, BMI>35, known OSA, bilateral transverse sinus stenosis) on Diamox 1000 mg QHS for 1-2 months, then gradual taper with ophthalmology follow-up

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Rebound Intracranial Hypertension

- If Diamox is prescribed, all **19** centers only supplement with potassium or sodium bicarbonate **as needed**
  - Consider monitoring magnesium due to urinary losses
- **3/19** centers consider **methazolamide** as it's better tolerated (starting dose varies by practice)

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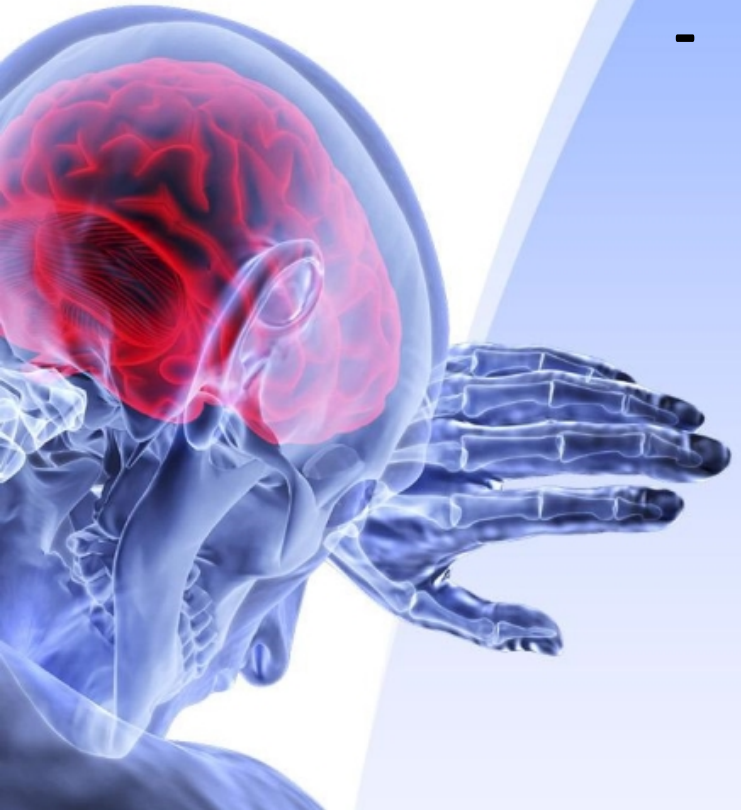
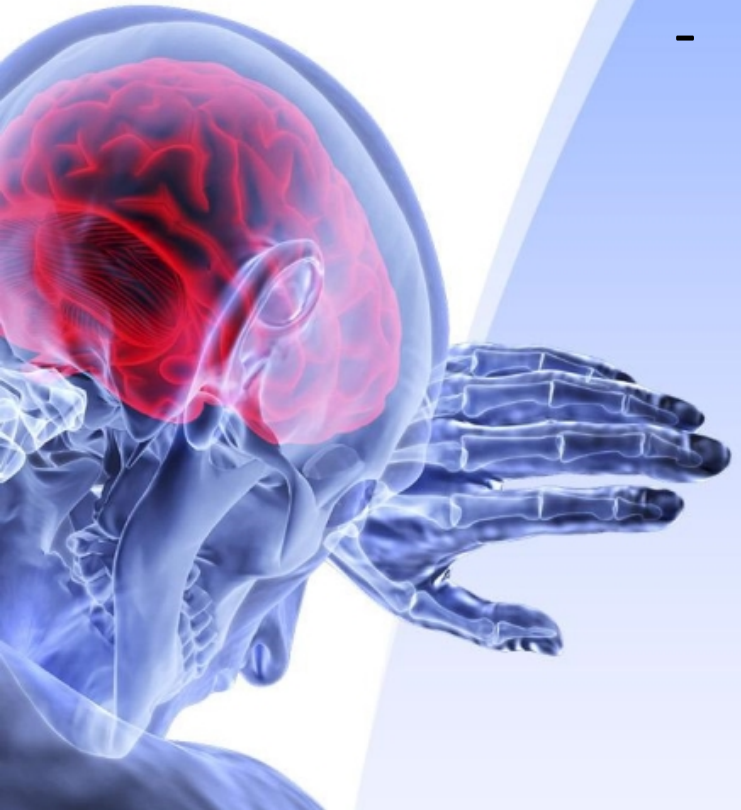
Rebound Intracranial Hypertension



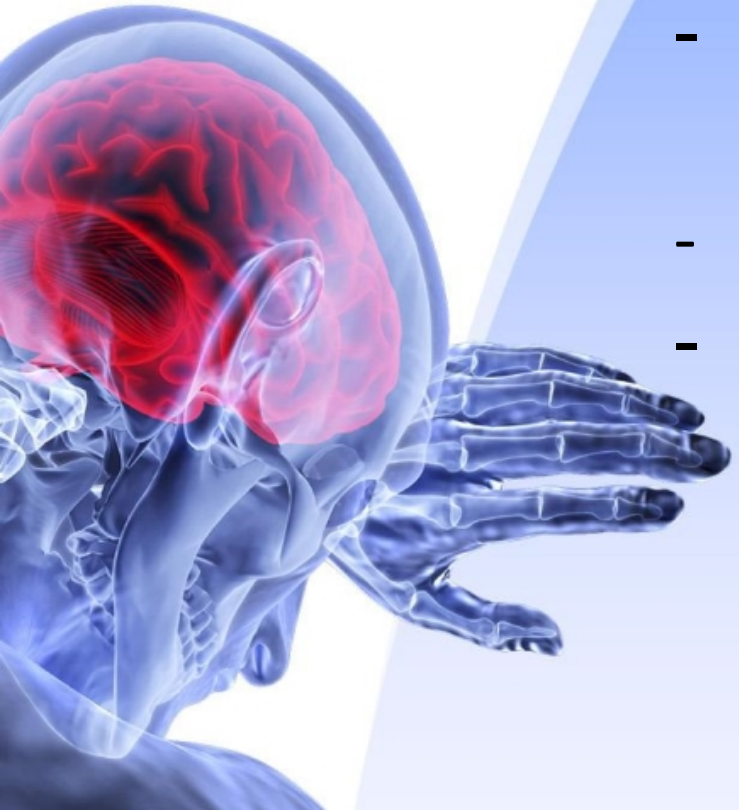
- **2/19** centers consider **topiramate** (Topamax) as 1st line treatment supplemented with or without Acetazolamide
  - If Topamax is prescribed, one center prescribes potassium citrate to prevent kidney stones

Rebound Intracranial Hypertension



- Other medications include:
  - **furosemide** (Lasix): 4/21
    - 2nd line for 3/4
    - 4th line for 1/4
  - Topamax: 1/21 use as 2nd line treatment and 2/21 use as 3rd line treatment

Rebound Intracranial Hypertension



- Lumbar puncture as the last resort: 3/21
- Ophthalmology evaluation: 2/21
- Admission for opioid pain relief: 1/21

Managing Expectations & Success of Treatment

1. **Individualized plan. Follow-up is necessary.**
    - One center in the UK reports that most patients are grateful for undergoing any type of treatment since there aren't many local centers
    - Video follow-up scheduled with nurse after 1 month post-treatment
    - Follow-up calls after 14 days and 3 months
    - Follow-up calls in 1 week, then 4-6 weeks patient to message or call if still having symptoms

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Managing Expectations & Success of Treatment

2. There is no quick fix and it's a process as well as a long and slow road to recovery. Repeated therapies is necessary, but don't give up and the medical team will guide and support through each step!

- Cautious optimism with the caveat that repeat interventions may be needed
- Try to provide hope and optimism for improvement, but also realistic that some patients will not improve, improve partially, or may require multiple treatments before they improve

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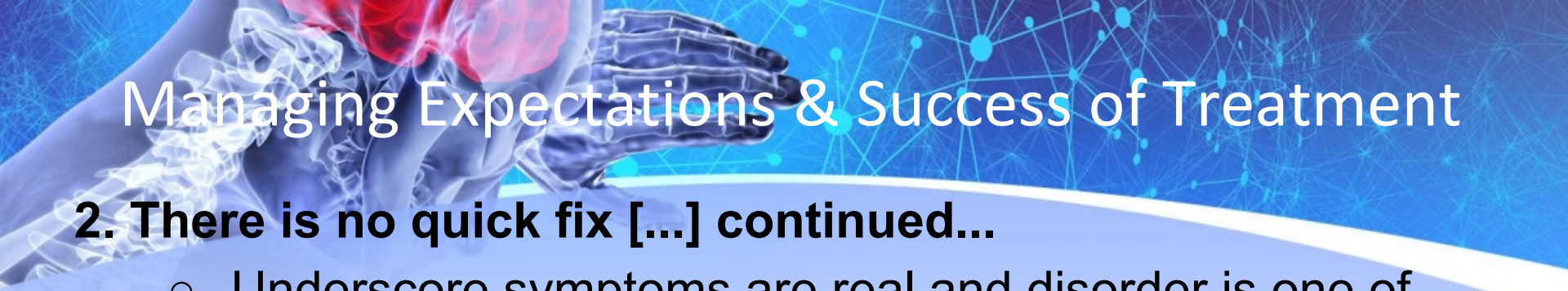

Managing Expectations & Success of Treatment

2. There is no quick fix [...] continued...

- Underscore symptoms are real and disorder is one of the disabling conditions that is ever treated
- Gradual improvement expected over the course of 6 weeks with continued improvement for 12 weeks thereafter
  - If symptoms reoccur, lie flat for 24-48 hours and monitor symptom resolution
  - May need to repeat diagnostic imaging or choose alternative diagnostic method

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Managing Expectations & Success of Treatment

3. Frank and realistic discussion about success rate

- Patients may feel worse before they feel better, particularly with regards to RIH but that is in itself a good sign that treatment has been successful
- Distinguish between what symptoms are due to CSF volume depletion and which are not (may not be)
- Symptom checklist – pre-and post to see which symptoms improved or worsened

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Managing Expectations & Success of Treatment

3. Frank discussion about success rate (continued)

- Probability rate of successful repair is 30% if it's unclear that the patient has a CSF leak and with repeated patching the rate increase to 65-70%
- Goal is improvement of symptoms and MRI abnormalities
- Offer realistic expectations depending on the possibility/probability of a leak

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Managing Expectations & Success of Treatment

3. Frank discussion about success rate (continued)

- Try to be realistic, but it depends on type of CSF leak
  - Most optimistic if it's a post-dural CSF leak versus dural tear
- Symptom recovery is based on duration of symptoms
  - Success of treatment depends on if the leak is isolated and etiology of the leak
  - Some symptoms may be permanent (i.e., muffled hearing or visual changes) or take longer to recover

Managing Expectations & Success of Treatment

3. Frank discussion about success rate (continued)

- Do not quote specific percentages of success rates
  - Surgery may be necessary in specific types of CSF leaks (i.e., ventral CSF leaks caused by bony spurs)
  - For CSF-venous fistulas, there is mixed data on the effectiveness of patching and it may be necessary to try more than one treatment before considering failure and considering surgery

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Managing Expectations & Success of Treatment

3. Frank discussion about success rate (continued)

- 70% chance of success with the first attempt with percutaneous treatment
- One international CSF leak center discusses potential benefits or risks of other treatment options that are more or less radical or experimental if patients are not quite satisfied with their recovery
- Another international CSF leak center reassure patients that the orthostatic HA should disappear immediately.
    - 2nd EBP is rare.

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Managing Expectations & Success of Treatment

4. **Support and resources**
   - CSF leak foundation including resources for safe re-conditioning

     https://spinalcsfleak.org

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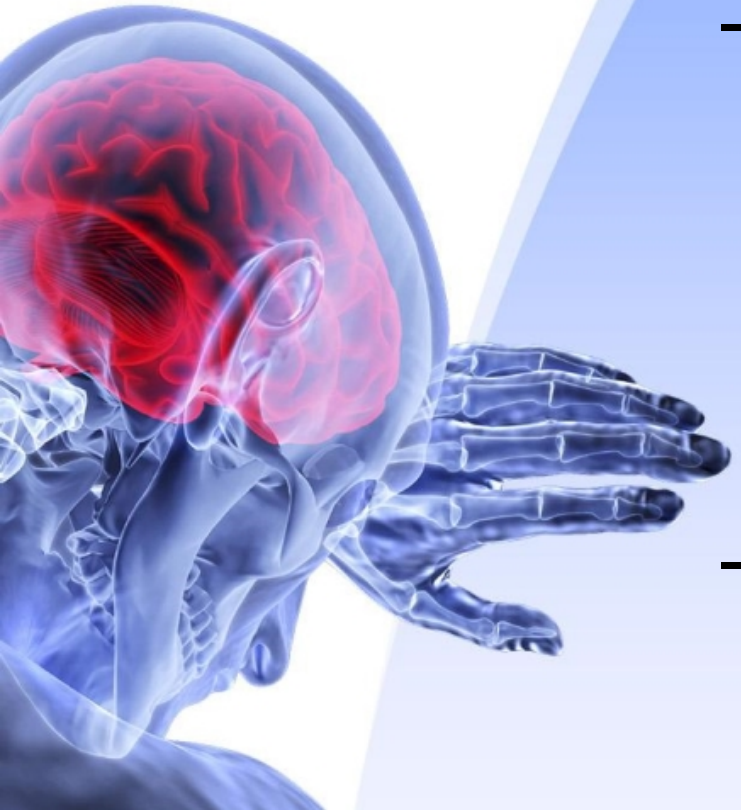

Limitations of the Results

- Management of expectations and success of treatment survey did not specify
  - Type of CSF leak
  - Objective and no objective evidence of a CSF leak
- Lack of independence (centers communicate with each other)

Summary

- Post-treatment considerations variability.
- No preferred mode of transportation post-treatment.
- Generally, no preventive or prophylactic treatment of coughing, nausea, vomiting, and constipation
- Generally, no preventive or prophylactic treatment of rebound intracranial hypertension
- Management of expectations and success of treatment is approached with cautious optimism and realistic goals.
- Treatment of a CSF leak is a long process and there is no quick fix, but our CSF leak experts are guiding patients every step of the way!

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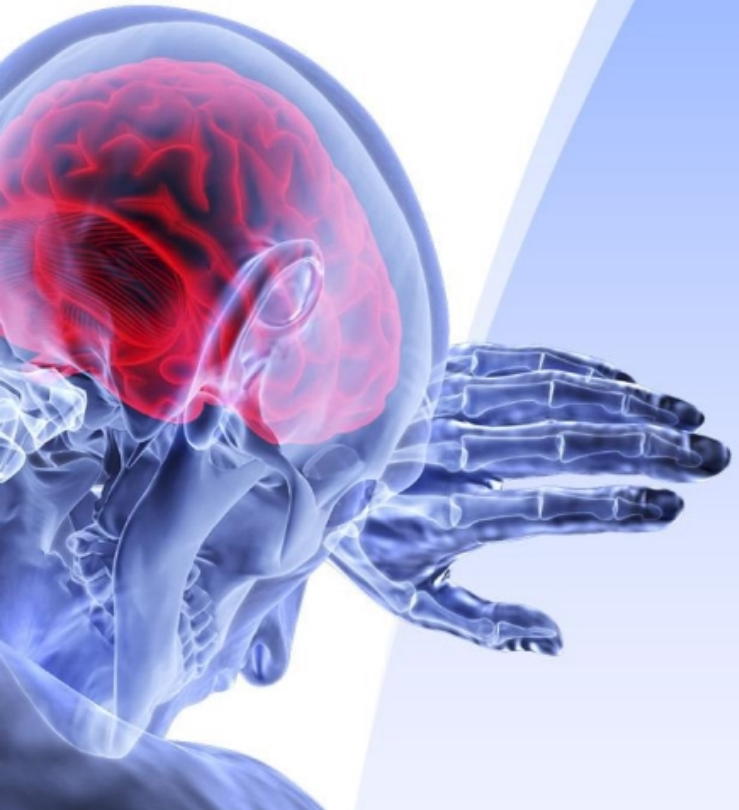

THANK YOU!