

Patient talk: The patching experience from the patient's point-of-view

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We will cover:

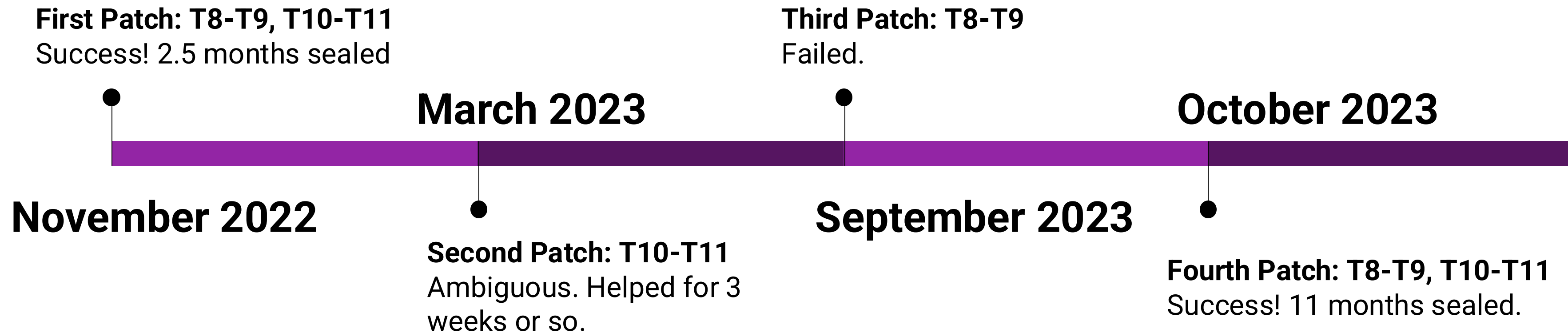
The Patching Experience

Practical Tips



Four Patches in One Year

Fibrin Glue Target Patching



The Patching Experience



First Patch – Before and During the Patch

- Easier than Expected
 - Time—approx. 15 minutes
 - Pain
 - There's wide variation in people's experiences



First Patch – Directly after the patch

- Almost Immediate Relief
- Some people, don't have immediate relief even with a successful patch. It can take 4-6 weeks

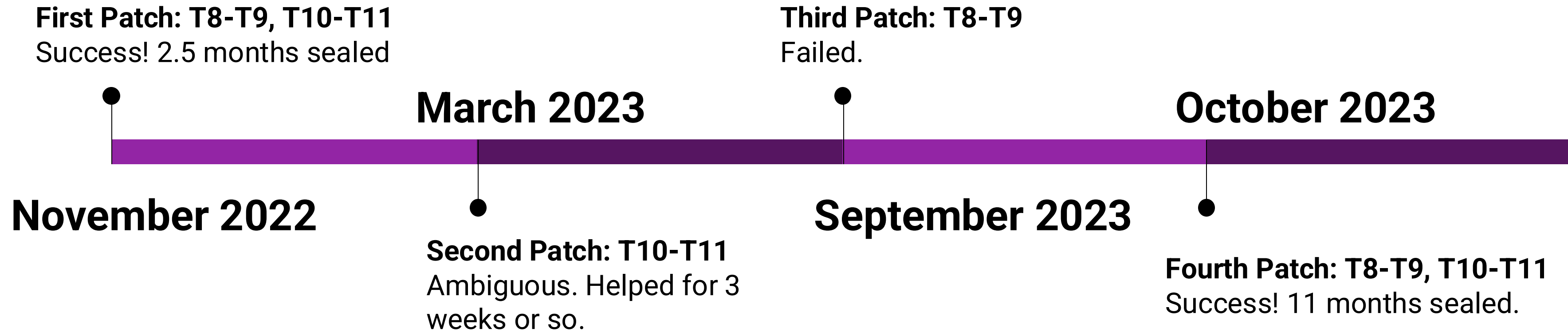


First Patch – The following days

- Post Patch Back Pain
 - For me, mild– managed with tylenol
 - For others, very intense
- Rebound Intracranial Hypertension
 - For me, very intense
 - But not everyone gets RIH post patch



Fourth Patch–Sealed!



Post Patch Symptom Changes

Some of these issues Resolved Immediately, some improved over time

BEFORE

1. Constant Headache 7/10
2. Neck Pain 7/10
3. Debilitating Foggy-Headedness
4. Fatigue-Sleeping 12-16 hours/day
5. Ambiguous Neurological Symptoms: ie Leg Numbness

AFTER

1. Daily Headache 2/10
2. No neck pain
3. No Foggy-Headedness
4. Energized on 6 hours of sleep
5. Improvement of Neurological Symptoms: Full Feeling in Legs Immediately post patch



Post Patch Symptom Changes

To be clear: I am not claiming that patching cured these symptoms, I am identifying correlations.

BEFORE

- 6. GI issues. ER visits. Daily Meds
- 7. Allergies. Monthly anaphylaxis. ER visits. Many Meds
- 8. Lowered Immune System. Recurrent Skin Infections. ER visits for Flu/Strep
- 9. POTS symptoms debilitating.
Standing BP avg 80/60

AFTER

- 6. No GI distress. No ER. No Meds
- 7. No anaphylaxis since first patch. No ER. Only two zyrtec a day
- 8. Better Immune System. No skin infections. No ER visits
- 9. POTS symptoms, so mild might be remission. Standing BP avg 110/70



I haven't been to the ER in a medical crisis since my first patch in 2022.

From 2017–2022, I went to the ER at least every 10 months having some kind of health crisis.



**Able to go hiking
again (6 miles+!!!)**

**Able to be outside
long enough to get
sunburned (sorry
to my
dermatologist!)**



Able to go out with friends and dance.





**Able to spend
time upright with
my nephews.**

**Not having to
make up games
where I lie down,
and they run
around me.**



Bridging the Gap

**I could do just about anything,
which is something I never
thought I'd be able to do again**



Practical Tips



Practical Tips – Doctor's Orders

1. 72 hours post patch flat
 - a. Thin pillow, or towel
2. No BLTs and no Stretching for 6 weeks
 - a. Log Rolling
3. Avoid increasing intra abdominal pressure
 - a. Ex: sneezing, bracing for exercise



Practical Tips – Preparation Months Before

1. Practice no BLTs until it was my default
 - a. Practiced Log Rolling
2. Gentle Movement of body parts far away from spine
 - a. Hand, Wrist, Elbow, Ankle, ect. Helped with joint pain.
3. Made My home accessible, and conducive to movement limitations



Practical Tips – Preparation Pre Patch

1. Be ready for fast questions
 - a. Providers don't have time for long messages via the patient portal. Set up an appointment, if you need to ask in depth questions
2. Like many other procedures
 - a. Wear comfortable clothing, maybe bring a snack to have afterwards, bring something to occupy you, etc.
3. Inform Provider about active infections or allergies



Practical Tips – Post-Patch

3 days flat

1. Prepare activities
 - a. Laptop Stand, Kindle, Music
2. Flat friendly foods
 - a. Finger Foods
3. So many pillows
4. Tylenol/ Pain Killers
5. Ice Packs



Practical Tips – Post Patch–6 weeks

1. Started reincorporating activities (physical and mental) as small as possible
 - a. Stepping Outside
2. Thought of everything as retraining my brain
3. Don't go to things, bring things to you
 - a. Grabber



Practical Tips – RIH

My first patch was successful, but my functioning didn't improve right away due to RIH. Things that helped me manage those symptoms:

1. Experimenting with different medication under doctor's guidance
2. Raising the head of my bed
3. Dandelion tea
4. Ice beanie
5. Avoiding Caffeine and Salt



**Look for the improvements
post patch **month by month,**
not day by day.**



My Journey Continues...

My provider and I believe I began **leaking again** a month ago at the beginning of October. We plan for me to have another patch.

Being sealed was **AWESOME**— better than anything I dared hope for since I was 14, and I have a good chance of having a successful patch again.

But even if I never get sealed again, and I only got to be sealed for 11 months, **those 11 months were still so much more than I ever dreamed.**



Thank you

