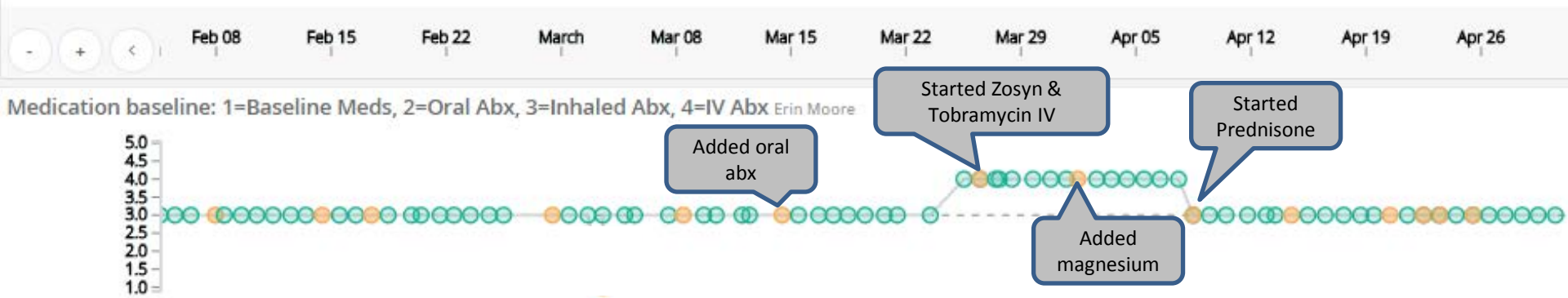
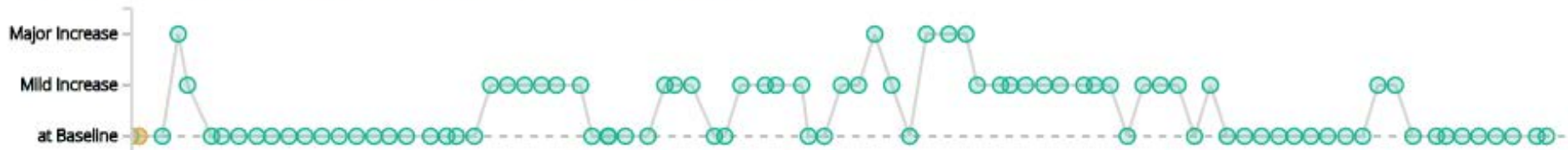




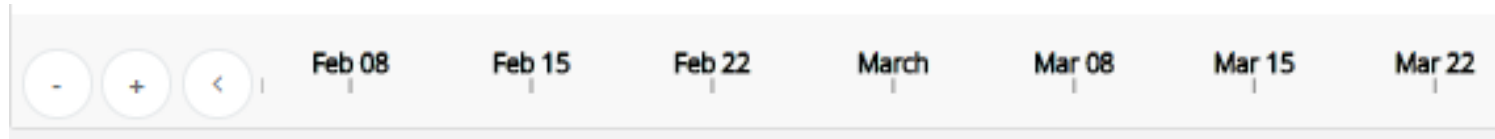
Understanding a change in symptoms



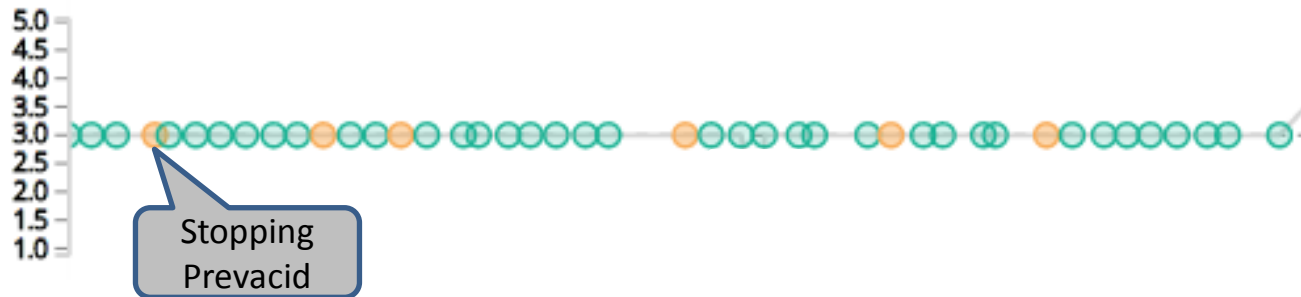
What has Drew's cough frequency been compared to his normal baseline? Erin Moore



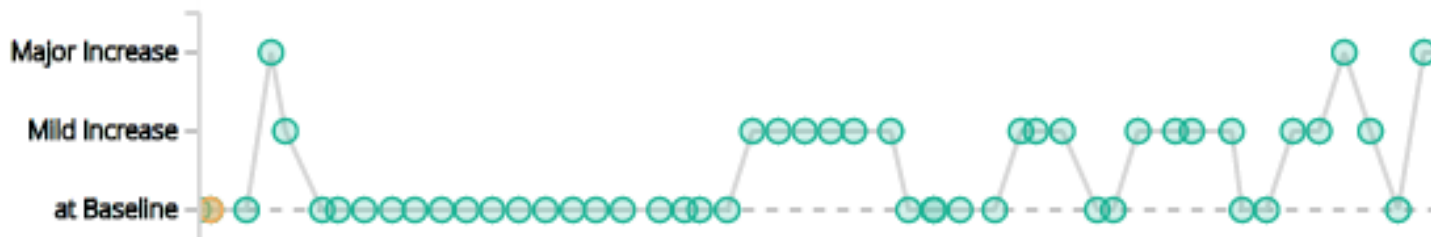
What was happening around the time the cough developed?



Medication baseline: 1=Baseline Meds, 2=Oral Abx, 3=Inhaled Abx, 4=IV Abx *Erin Moore*

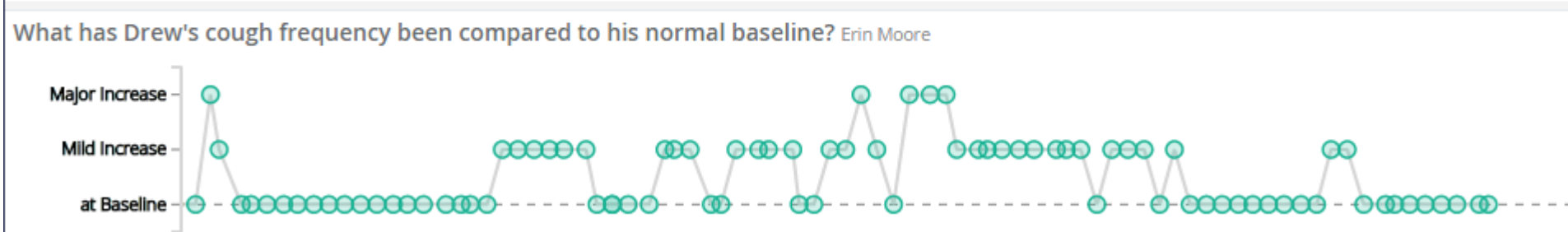
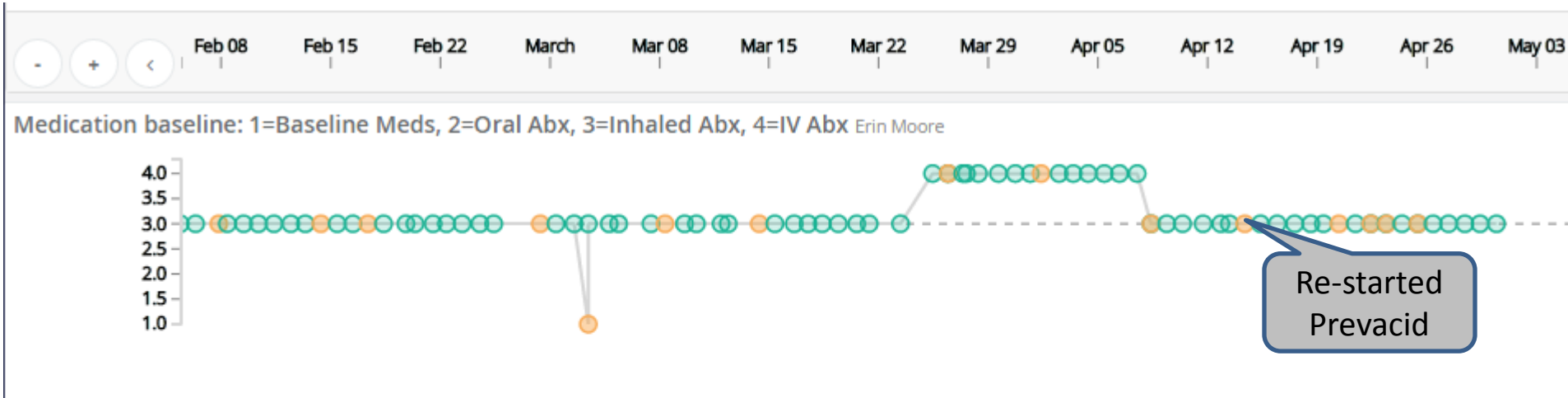


What has Drew's cough frequency been compared to his normal baseline? *Erin Moore*



Finding our answer – creating a hypothesis

- On April 14 we restarted Plevacid
- By April 21 we were back to our baseline and remain cough free today!



The cost

- 4 days of missed days of school
- 18 unplanned visits over 14 days from home health nurses & countless hours of calls from HCPs helping to coordinate his care
- Many hours of missed work for me / my husband
- Drew stopping swimming because of IV line leading to need for ENT intervention for sinus issues
- Restricted family activities
- Anxiety over overusing the only antibiotic that works for him vs sub optimal medication choice

Who should be learning?

Experts

- Expert researchers
- Expert clinicians



Everyone

- Patients
- Families
- Clinicians
- Researchers





Rare Diseases

