Clinic Visits : Virtual, Telemedicine or In-Person

Date: _____

Patient Name: _____ Patient ID: _____

Clinician: _____

Use this form to capture clinic notes including vitals, labs and parent reported changes. Complete one (1) survey **per visit.**

Please note: this form includes general clinical questions, lab results, overall assessments, carvedilol-specific questions as well as a parent-reported assessment that must be discussed with the parent *during the clinic visit.*

Clinical Assessment

1. **Was this visit in person or virtual?** ☐ In person Virtual ☐ Telemedicine

2. **Blood Pressure** _____ *(Systolic/Diastolic)*

3. **Heart Rate** _____ *BPM*

4. **Was an EKG conducted today?** ☐ Yes ☐ No

5. **Results of EKG- Normal** ☐ Yes ☐ No

If No-
- ☐ Bradycardia
- ☐ Long qTC
- ☐ Other

Specify Other:

_____

_____

6. **Describe child's overall health today compared to their baseline:**

_____

_____

7. **Presence of new rash?** ☐ Yes ☐ No
Parent report or upon exam

8. **Other new health issues?** ☐ Yes ☐ No ☐ Not Assessed ☐ Don't Know

If Yes- briefly describe:

_____

Lab Results

Hematologic Results

9. **Was the CBC lab test completed?** ☐ Yes ☐ No

If No- Skip to #11

10. **Were any results outside normal for this patient?** ☐ Yes ☐ No

If No-
- ☐ Anemia
- ☐ Leukopenia
- ☐ Thrombocytopenia
- ☐ Other

Specify Other:

_____

_____

Metabolic Results

11. **Was a CMP panel completed?** ☐ Yes ☐ No

If No- Skip to 13

12. **Were there any CMP measures that were outside the normal range for this patient?** ☐ Yes ☐ No

If Yes Check all that apply-
- ☐ Hyperglycemia
- ☐ BUN elevation
- ☐ AST/ALT ___/___
- ☐ Other

Specify Other:

_____

_____

EEG Results

13. **Was an EEG conducted in the past 30 days?** ☐ Yes ☐ No

If No - Skip to #16

If Yes - What Was Duration:

_____

EEG Results (Cont.)

14. **Were seizures captured on the EEG** ☐ Yes ☐ No

If Yes - How many? _____

Average # of seizures per hour _____

What did EEG show about changes in seizures

_____

15. **Has the background changed compared to previous EEG?** ☐ Yes ☐ No

If Yes - briefly describe:

_____

Carvedilol

16. **How many days has the participant been administered Carvedilol?** _____ *Days*

17. **What are your recommendations for Carvedilol dosage after todays clinic visit?**

☐ Increase Dose
☐ Continue on Same Dose
☐ Reduce Dose
☐ Discontinue use

If you are not recommending an increased dose, explain the predominant reason for your decision:

_____

18. **Do you feel the patient should be withdrawn from this study?** ☐ Yes ☐ No

If Yes- Explain

_____

Parent Report Questions

19. **Any changes in medications since last visit?** ☐ Yes ☐ No

If Yes- briefly describe:

Parent Comments:

20. **How did this last month compare to the month prior in terms of daily seizure count?**

☐ Better than last month
☐ Worse than last month
☐ No change
☐ Not sure

Parent Comments:

	Better	Worse	No Change	Not sure
Any changes in the NUMBER of seizures since last visit?	☐	☐	☐	☐
Any changes in the TYPES of seizures since last visit?	☐	☐	☐	☐
Any changes in the DURATION of seizures since last visit?	☐	☐	☐	☐
Any changes in the RECOVERY TIME for seizures since last visit?	☐	☐	☐	☐
Any changes in overall health (including seizures) since last visit?	☐	☐	☐	☐

	Better	Worse	No Change	Not sure
Any changes in time to fall asleep since last visit?	☐	☐	☐	☐
Any changes in sleep duration since last visit?	☐	☐	☐	☐
Any changes in sleep quality since last visit?	☐	☐	☐	☐
Any changes in expressive language and vocaliztions since last visit?	☐	☐	☐	☐
Any changes in receptive language since last visit	☐	☐	☐	☐
Any changes in behavior since last visit?	☐	☐	☐	☐
Any changes in swallowing since last visit?	☐	☐	☐	☐
Any changes in reflux since last visit?	☐	☐	☐	☐
Any changes in constipation since last visit?	☐	☐	☐	☐
Any changes in use of hands since last visit?	☐	☐	☐	☐
Any changes in stability of neck since last visit?	☐	☐	☐	☐
Any changes in vision or eye tracking since last visit?	☐	☐	☐	☐