**PICECAP FOLLOW-UP CHECKLIST to Maximize Trial Success**

**Subject ID:**

**Subject Name: LAR Name: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**Around enrollment**

* Complete the PedsQL with the family within 72 hours of enrollment. Best practice: Complete via interview.
* Review PedsQL (complete? Correct?) Upload the PedsQL to your drop box.
* Obtain contact information using the [Participant Contact Information Form](https://siren.network/wp-content/uploads/2025/02/final_p-icecap_participant_contact_form_8-21-23.pdf).
* Build rapport with family.

**Around hospital discharge (or just prior to 2 months post CA if still hospitalized)**

* Remind caregiver that the study involves 3 follow-up time points Let them know that you will contact them:

1. Around 2 mo post CA, (Date:\_\_\_\_\_\_\_\_\_\_\_\_\_)to set up the first (3-month) call with Kennedy Krieger.
2. Around 6-9 mo post CA, (Date range:**\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_)** to schedule the onsite neurological examination which will take place after the last telephone interview.
3. Around11 mo post CA, (Date:\_\_\_\_\_\_\_\_\_\_\_\_) to set up the final (12-month) call with Kennedy Krieger.

* Review contact information form with caregiver and add to it, upload to drop box.

**At 2 months post arrest** **(Date:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_)**

* Use the [contact tracking log](https://siren.network/wp-content/uploads/2025/02/Contact-Tracking-Log.pdf) to record attempts to reach caregiver.
* Reach out to [picecap@kennedykrieger.org](mailto:picecap@kennedykrieger.org) early if you are having difficulty reaching the caregiver.
* Contact caregiver to confirm the child is alive and arrange date/time for 3-month phone call with KKI.
* Remind caregiver of your next 2 points of contact after the 3-month interview (approximate date you will be calling to schedule the neuro exam and the final interview).
* Update your Participant Contact Form. Include date/time for phone call if obtained, or best date/time to reach caregiver.
* Upload the updated Participant Contact Form to your drop box.

**At 6-9 months post arrest (Date: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_)**

* Coordinate with your study neurologist to obtain an appointment 3-6 weeks after 12-month post CA
  + (**Date range: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_-\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_) Note: this can be after the window.**
* Remind caregiver of your last point of contact (date) at 11months.

**At 11 months post arrest (Date: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_)**

* Use the [contact tracking log](https://siren.network/wp-content/uploads/2025/02/Contact-Tracking-Log.pdf) to record attempts to reach caregiver.
* Reach out to [picecap@kennedykrieger.org](mailto:picecap@kennedykrieger.org) if you are having difficulty reaching the caregiver.
* Contact caregiver to confirm the child is alive and arrange date/time for 12-month phone call with KKI.
* Update Participant Contact Form with date/time for phone call, or best date/time to reach caregiver, & date of on-site neuro exam.
* Upload the updated Participant Contact Form to your drop box.

**General tips**

**Connecting with family during hospitalization**

If the child is not doing well, it can be difficult to build rapport. Stopping by, reminding them who you are and asking if you can get them anything is a good idea. Interactions can be small and short.

**Connecting with family during follow up phone calls**

Continue to build rapport

Make sure child is alive and with family

Identify any stressors that could impact follow-up and include such information on the contact form for KKI.

**Difficulty reaching a caregiver**

If it is very difficult to connect with a caregiver:

* + Try at different times of day and in the evenings and on weekends
  + Use different modes of communication: Leave voicemail, text, email.

Connect with KKI [picecap@kennedykrieger.org](mailto:picecap@kennedykrieger.org) *early*. They have many good suggestions, that are easy to do.

**Timing Reminder:**

* You need to reach the caregiver within the 2 weeks following the 2-month post arrest date.
* You need to reach the caregiver within the 2 weeks following the 11-month post arrest date.
* Use the [window calculator](https://siren.network/wp-content/uploads/2025/02/3_and_12_month_post_ca_window_calculator_mw_edits.xlsx) if you are unsure of when to start reaching out to the caregiver.
* It is ok to schedule the neurology exam sometime within the month **after** the12-month window

**If you are more of a visual person, set up a study calendar so you know when the pertinent time points are (2 months, 6-9 months and 11 months)!**