

Survey: EMERGENCY PLANNING FOR PARENTS/FAMILY MEMBERS

Purpose: Many children who come to the Emergency Room are medically fragile children with complicated disorders and very specialized needs. Several specialists often manage them. Information from this survey will help the Region 4 Genetics Collaborative Care Coordination Group make recommendations to help specialists, caregivers, and emergency department staff best meet the needs of these children

1. Do you have a written emergency plan for your child?
 Yes
 No

2. If yes, what is that plan?
 Help or Emergency care letter from Specialist/Primary Care Provider
 Emergency ID Alert
 Parent created letter/summary of information
 Care plan form that parent created
 Wallet alert with disorder/disease information and clinical contact
 Web-based emergency plan
 Medical Health Care System Intranet-based Health Plan
 Other (please specify) _____

3. Have you ever used the plan in an emergency?
 Yes
 No
If yes, was it useful?
 Yes
 No

4. At what point did you first create an emergency plan?
 When my child was first diagnosed
 Planning for travel/an out of town trip
 Entering school
 Other. Please Specify _____

5. Are you comfortable with the plan the way it is?
 Yes. Please describe: _____
 No. Please describe: _____

6. What are your biggest concerns about an emergency?

7. Do you have a packed bag ready in case of an emergency?
 Yes
 No
If yes, what are the essentials you keep in it? _____

8. Do you typically call the on-call specialist before going to the ER?
 Yes
 No

9. Have you taken your child to the emergency room in the past *for a disorder related situation*?
 Yes
 No
10. Have you taken your child to the emergency room in the past for a *“non-disorder related situation” (which may or may not be complicated by your child’s disorder)*?
 Yes
 No
11. Do you feel valued when at the ER?
 Yes
 No
12. Do you feel like you are listened to at the ER?
 Yes
 No
13. In your opinion, do the ER staff have a good understanding of what your child needs?
 Yes
 No
14. Is your specialist(s) communicating with the ER providers during the emergency?
 Yes
 No
15. If you have used a plan can you compare your experience before you had a plan and after you had a plan?
16. Please order, in priority from 1 - 8, your preference for providing information to the ER staff in an emergency. 1 is your first choice.
- Help or Emergency care letter from Specialist/Primary Care Provider
 - Emergency ID Alert
 - Parent created letter/summary of information
 - Care plan form that parent created
 - Wallet alert with disorder/disease information and clinical contact
 - Web-based emergency plan
 - Medical Health Care System Intranet-based Health Plan
 - Other (please specify) _____
17. What concerns do you have about a web-based emergency information system?
18. Anything else that you would like to add?