

Planning for Health Emergencies

a toolkit for families of children with special health needs

Any trip to the emergency room is stressful. For parents whose children have special health needs, it can be especially complicated. The right information needs to get to the right people, and quickly. Planning ahead for emergencies can help everyone involved and give you peace of mind.

This toolkit was developed by parents of children with special health needs in collaboration with emergency medical professionals. The tools will help you be ready if your child must go to the emergency room.

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Questions? Contact us.
We're here to help.
1-855-323-6744
www.oregonfamilytofamily.org



Family's Emergency Support Team

Someone who will be responsible for keeping my family and friends up to date on our situation

Name _____
Phone # _____

Someone to go with me to the emergency room

Name _____
Phone # _____

Someone who can provide financial support until emergency is over

Name _____
Phone # _____

Someone to be with me at the hospital

Name _____
Phone # _____

Someone who can provide a ride for me or my children

Name _____
Phone # _____

Someone for spiritual support or prayer

Name _____
Phone # _____

Someone to cook a meal, make kids' lunches or [arrange a Meal Train](#)

Name _____
Phone # _____

Someone to run errands

Name _____
Phone # _____

Someone to help my kids with homework if I cannot be there

Name _____
Phone # _____

Someone to take care of pets

Name _____
Phone # _____

Someone to keep in touch with my employer

Name _____
Phone # _____
Name _____
Employer
Phone # _____

Someone to communicate with the school for us, get homework, etc.

Name _____
Phone # _____

Someone to help with laundry or housework

Name _____
Phone # _____

Before a Health Emergency

a checklist to help you prepare

- Think about who is on your Family's Emergency Support Team. Fill out the worksheet on the opposite page, and keep it with your emergency documents.

- Meet with your child or youth's doctor(s) to talk about:
 - What is an emergency and what to do.
 - Whether your child needs an Emergency Protocol Letter or the ACEP/AAP form (examples follow).
 - What information should be included in the HERO Kids Registry (see below).

- Register your child or youth with [HERO Kids Registry](https://www.herokidsregistry.org) (www.herokidsregistry.org). HERO Kids Registry is a system that lets families and young adults record critical health information that first responders and hospital providers can easily access in an emergency. The registry is secure, and there is no cost to use it. Their website [answers common questions](#) and tells you [how to register](#). If you have questions or need help, call the business office at 833-770-4376, or email herokids@ohsu.edu.

- When you get a HERO Kids Registry ID number, share it with school staff, caregivers, health care providers, and others who have regular contact with your child or youth.

- Arrange a visit with your local ambulance agency or fire station.
 - Familiarize your child or youth with the emergency medical services (EMS) providers and their emergency vehicles.
 - Show EMS providers your child's or youth's specialized equipment.
 - Give EMS providers your child's or youth's HERO Kids Registry ID number.

Emergency Protocol

An “emergency protocol” is a letter or document from a child’s or young adult's doctor, with specific information for emergency department providers. The emergency protocol includes key information about how to assess, diagnose, or treat this patient in an emergency.

Talk to the doctor about whether your child or young adult should have an emergency protocol. If so, the doctor can use the example below, or simply write the protocol on their letterhead. Family members or young adults should keep the emergency protocol document somewhere safe, and upload it to the [HERO Kids Registry](#).

EMERGENCY PROTOCOL EXAMPLE

Patient Name	Jane Vang
Date of Birth	2/12/2016
Emergency protocol from	Susan Smith MD (Jane’s PCP) Kiddo Family Practice, Portland OR
Contact(s) for questions re: patient care	<ul style="list-style-type: none">• Susan Smith MD, Kiddo Family Practice, 503-999-0000• OHSU Pediatric Neurology Fellow: 503-000-9999
Condition(s) that might result in an ED visit	<ul style="list-style-type: none">• Complex generalized seizures• Anxiety disorder
Prescribed medications and equipment	<ul style="list-style-type: none">• Phenobarbital• Keppra
Signs or symptoms to be aware of	<ul style="list-style-type: none">• Watch for oxygen desaturation and inadequate ventilation with seizures.• Jane’s seizures often begin with staring and lip smacking.
Emergency management recommendations (e.g., unique vital signs, assessments, therapeutic strategies)	<ul style="list-style-type: none">• Lorazepam 0.1mg/kg IV for seizures longer than 5 minutes, repeat once• Phenobarbital 10mg/kg IV load if seizures do not stop with 2 doses of lorazepam
Language or communication needs	<ul style="list-style-type: none">• Family speaks limited English. Request Hmong interpreter.• Jane understands but does not use spoken language.
Patient or family concerns (e.g., past medical trauma, soothing strategies)	<ul style="list-style-type: none">• Use Child Life when possible.• Jane experiences severe anxiety. May physically resist medical intervention.• Allow a family member to explain next steps to Jane if possible.• Jane fears needles. Does better with a parent hugging her.• Jane has a comfort item (a fleece “Frozen” blanket). Best if she can keep that blanket with her.
Other information (e.g., allergies, potential treatment side effects)	<ul style="list-style-type: none">• Jane is allergic to penicillin.



Last name:

Emergency Information Form for Children With Special Needs



American Academy of Pediatrics



Date form completed	Revised	Initials
By Whom	Revised	Initials

Name:		Birth date:	Nickname:
Home Address:		Home/Work Phone:	
Parent/Guardian:	Emergency Contact Names & Relationship:		
Signature/Consent*:			
Primary Language:	Phone Number(s):		
Physicians:			
Primary care physician:	Emergency Phone:		
	Fax:		
Current Specialty physician: Specialty:	Emergency Phone:		
	Fax:		
Current Specialty physician: Specialty:	Emergency Phone:		
	Fax:		
Anticipated Primary ED:	Pharmacy:		
Anticipated Tertiary Care Center:			

Diagnoses/Past Procedures/Physical Exam:	
1.	Baseline physical findings:
2.	
3.	Baseline vital signs:
4.	
Synopsis:	
	Baseline neurological status:

*Consent for release of this form to health care providers

Diagnoses/Past Procedures/Physical Exam continued:

Medications:	Significant baseline ancillary findings (lab, x-ray, ECG):
1. _____	_____
2. _____	_____
3. _____	_____
4. _____	Prostheses/Appliances/Advanced Technology Devices:
5. _____	_____
6. _____	_____

Management Data:

Allergies: Medications/Foods to be avoided	and why:
1. _____	_____
2. _____	_____
3. _____	_____
Procedures to be avoided	and why:
1. _____	_____
2. _____	_____
3. _____	_____

Immunizations

Dates						Dates					
DPT						Hep B					
OPV						Varicella					
MMR						TB status					
HIB						Other					

Antibiotic prophylaxis:

Indication:

Medication and dose:

Common Presenting Problems/Findings With Specific Suggested Managements

Problem	Suggested Diagnostic Studies	Treatment Considerations

Comments on child, family, or other specific medical issues:

Physician/Provider Signature: _____ **Print Name:** _____

Before the Hospital (EMS/Ambulance)

When Emergency Medical Services (EMS/paramedics) arrive:

- Tell them if your child is registered with [HERO Kids Registry](#). Give them the HERO Kids Registry ID number or the printed HERO Kids form.
- Explain how the child is presenting differently today. Say what was out of the ordinary that made you call 911. For example: “He can usually make eye contact and smile, but he is not doing that now.”
- Tell them what medications were given recently (with dosages), especially if they are different from what the child usually takes.
- Tell them what is most important right now. For example, do you want EMS to treat the child where they are, transport them to the nearest hospital, or something else?
- Offer EMS any specialized equipment or supplies (such as g-tubes, suction, etc.). Bring what the child needs to the hospital.
- Have Medical Power of Attorney forms on-hand if your child is over 18, or if there are complex custody issues.

At the Emergency Department

- Tell them if your child is registered with [HERO Kids Registry](#).
- Tell them if your child has an Emergency Protocol Letter or an [ACEP/AAP Emergency Form](#) in HERO Kids Registry.
- Give emergency room staff helpful information like:
 - Medical fears or triggers such as white coats, certain smells, etc.
 - Child’s preferred name, position of comfort, etc.
- Before leaving the emergency department:
 - Connect with a case manager or social worker to see what support is available.
 - Gather your child’s personal equipment or supplies.

Tips from Parents of Children with Special Health Needs

Taking care of YOURSELF during an emergency

In an emergency, or when traveling to the emergency room, try to:

- Take a moment for yourself
- **BREATHE!**
- Have your own supplies/meds/vitamins etc in one place in case you have to go quickly
- Make a plan for an emergency trip and think about a back-up plan, too
- Stay in the moment
- If you can't be calm, let another responsible person take over for you until you are
- Remember that your child's safety is what matters most
- **BREATHE!**
- Drink water
- Eat nutritious food
- Wash your hands
- Ask all the questions you need
- If something doesn't sit right with you, say so; follow your instincts
- Be nice to yourself; this is hard
- Be ready for a long wait
- Download a funny book to escape worry
- Get up and move around
- Talk to other families in the waiting room
- Keep your heart and mind open so you can be receptive to incoming advice
- Be nice to nurses and others while advocating
- **BREATHE!**
- Tell support people what you need

These tips are offered with love from the Parent Partners of the Oregon Family to Family Health Information Center.

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