

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.

updated October 2025



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 for spiritual support or prayer

Name _____
Phone # _____

Someone to run errands

Name _____
Phone # _____

Someone to take care of pets

Name _____
Phone # _____

Someone to help with laundry or housework

Name _____
Phone # _____

Someone to keep in touch with my employer

Name _____
Phone # _____
Name _____
Phone # _____
Employer

Someone who can provide a ride for me or my children

Name _____
Phone # _____

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

Name _____
Phone # _____

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

Name _____
Phone # _____

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

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](http://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.


Health Emergency Protocol

A “health emergency protocol” is a formal document from a child’s or young adult’s licensed healthcare provider, with specific information for emergency department providers. It is for any patient whose physical or mental health condition(s) require specific treatment during a medical emergency.

Talk to the healthcare provider about whether your child or young adult should have a health emergency protocol. If so, they can write the protocol on their letterhead or on the Oregon Health Emergency Protocol Form which is available here, <https://tinyurl.com/emprot>.

Family members or young adults should have a copy of the health emergency protocol available for emergencies, and upload it to the HERO Kids Registry here, <http://www.herokidsregistry.org>.

EMERGENCY PROTOCOL EXAMPLE

HIPAA PERMITS DISCLOSURE TO HEALTH CARE PROFESSIONALS & ELECTRONIC REGISTRY AS NECESSARY FOR TREATMENT			
Oregon Health Emergency Protocol			
Patient's Last Name: Example	Suffix:	Patient's First Name: Child	Patient's Middle Name:
Date of Birth: (mm/dd/yyyy): 02 / 16 / 2016	Pronouns: She/her	Address (street/city/zip): 1234 Example Street, Portland, OR 00000	
HEALTH EMERGENCY MANAGEMENT RECOMMENDATIONS:			
<i>Use the field below to describe actions that should be taken by Emergency Department providers in response to a specific medical emergency for a patient with complex physical health and/or mental health condition(s). This may include: primary and secondary diagnoses, medications/fluids/specific treatments, and contact information for emergency consult.</i>			
Condition: Complex generalized seizures			
Recommendations: 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 Consult call: Doctor Smith MD, Kiddo Family Practice, 503-999-0000 or OHSU Pediatric Neurology Fellow: 503-000-9999 HERO Kids: Has a HERO Kids registration, ID# OR00000			
ATTESTATION of MD/DO/NP/PA/ND (REQUIRED)			
<i>By signing below, I attest that these care recommendations are the current best course of action for the patient should they experience a medical emergency involving the complex physical health and/or mental health condition(s) described above.</i>			
MD/DO/NP/PA/ND Printed Name: required Doctor Smith, MD	Signer's Phone Number: 503-999-0000	Consult Phone Number: 503-999-0000	
MD/DO/NP/PA/ND Signature: required 	Date Signed: required 1/21/25	Signer's License Number: MD000000	

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Last name:

Emergency Information Form for Children With Special Needs



American Academy
of Pediatrics



Date form
completed
By Whom

Revised
Revised

Initials
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:

Diagnoses/Past Procedures/Physical Exam continued:

Medications:

Significant baseline ancillary findings (lab, x-ray, ECG):

1.

2.

3.

4.

5.

6.

Prostheses/Appliances/Advanced Technology Devices:

Management Data:**Allergies: Medications/Foods to be avoided****and why:**

1.

2.

3.

Procedures to be avoided**and why:**

1.

2.

3.

Immunizations**Dates**

DPT

OPV

MMR

HIB

Dates

Hep B

Varicella

TB status

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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