

## Appendix

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# Health Emergency Ready Oregon

In an emergency, every moment counts.



## Information for families

### What is HERO Kids Registry?

HERO Kids Registry is a voluntary, no-cost system that lets any Oregon family share critical information about their child's health *before* an emergency. The information can be quickly and easily accessed by emergency medical services (EMS) and hospital emergency department (ED) providers, so they have the information they need when they need it.

### Who is HERO Kids for?

**HERO Kids is for any Oregon child or young adult (through age 26).** It is especially useful for young people with complicated or chronic health conditions, and for those who experience developmental disabilities or mental health conditions.

### Why should I register my child?

In an emergency, every moment counts. By registering with HERO Kids, you give EMS and ED providers a head start on understanding your child's medical history, unique needs and individualized supports. For example, it helps emergency responders to know if a young patient is non-verbal.

### How does it work?

1. In an emergency, the person calling 911 gives the dispatchers your child's HERO Kids Registry ID number, or just tells them the child is registered.
2. Once EMS and ED providers know your child is registered, they can get the information you provided in less than 90 seconds, through a confidential provider line or the [Emergency Department Information Exchange](#).

### Who can access the HERO Kids Registry, and is it secure?

To protect privacy and confidentiality, only the following people have access to the Registry:

- The parent or legal guardian who registers the child
- Young adults who register themselves
- HERO Kids Registry staff, who are trained to comply with all health privacy laws (HIPAA)
- Oregon EMS and Oregon ED providers who are treating the child



More information  
[www.herokidsregistry.org](http://www.herokidsregistry.org)  
[herokids@ohsu.edu](mailto:herokids@ohsu.edu)  
Business office: 833-770-4376



## Who updates my child's registration when there's a change?

Parents or legal guardians update their child's HERO Kids Registry information as needed. Young adults who register themselves update their own information.

## How do I register my child?

1. Gather health information emergency responders might need. This includes diagnoses, medications and allergies, emergency protocol letters, emergency information forms, etc.. After-visit summaries can be a good source for much of this information.
2. Register online (computer or tablet only) at [www.herokidsregistry.org](http://www.herokidsregistry.org). If you prefer paper, you can request the form by emailing [herokids@ohsu.edu](mailto:herokids@ohsu.edu).
3. HERO Kids Registry staff activate the registration. If there is a problem, they will get in touch with you to resolve it.
4. In a few weeks, you will get a confirmation packet in the mail with a welcome letter, stickers, and a backpack tag with the HERO Kids Registry ID number on it.

NOTE: Young adults aged 15-26 years can register themselves.

## Can my child's doctor create or update the registration?

Only parents, legal guardians, and young adults aged 15-26 can create or change a registration. You can work with health care providers to make sure the information is correct and complete.

## Does HERO Kids train EMS to manage complex medical or behavioral health conditions?

No. HERO Kids shares the information you give to the Registry, to help them provide better-informed emergency care and services.

## How do I update information or cancel registration?

Minor changes to contact information can be made by calling the registry business office. You can update the registration online any time. You can cancel by email or mail. Details are included in the packet you get in the mail after you register.

## Is there anything else I should do to prepare for a medical emergency?

- Make an appointment to visit your local EMS agency or fire department with your child or young adult. Let the emergency responders know that your child or young adult is registered with HERO Kids Registry.
- Share the Registry ID with health care providers, school staff, caregivers, and family members.
- Review the [Planning for Health Emergencies toolkit](#) at [www.oregonfamilytofamily.org](http://www.oregonfamilytofamily.org).

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## Information for Emergency Medical Services

### What is HERO Kids Registry?

HERO Kids Registry is a voluntary, no-cost system that lets any Oregon family share critical information about their child's health *before* an emergency. The information can be quickly and easily accessed by emergency medical services (EMS) and hospital emergency department (ED) providers, ensuring they have the information they need when they need it.

### Who is HERO Kids for?

**HERO Kids is available to any Oregon child or young adult ages 0-26.** HERO Kids is especially useful for medically complex children and young adults who experience chronic health conditions, developmental disabilities, and/or mental or behavioral health conditions.

### Why should EMS access the Registry?

HERO Kids Registry gives EMS and ED providers a head start on understanding a child's medical history and unique needs. The Registry also shares information that can help with care or comfort. For example: an infant in respiratory distress has a known difficult airway, or a child with a seizure disorder does not respond to typical seizure-controlling medications.

### What information can EMS get from the Registry?

- Parent or legal guardian contact information
- Approach considerations
- Medical and/or behavioral conditions
- POLST information via the Oregon POLST Registry
- Emergency Protocol Letters
- Emergency Information Forms
- Alerts
- Allergies
- Medications
- Hospital preference
- Safe words

### When should EMS access the Registry?

- When dispatch, parent, legal guardian, or young adult provides a Registry ID number
- When they see a HERO Kids Registry ID sticker or backpack tag
- When they have basic demographics for a pediatric patient

Example Registry ID Sticker



### How does EMS access the Registry, and how fast is information available?

A confidential hotline phone number is available to EMS 24/7. When EMS calls the hotline and provides the child's demographic information or Registry ID number, information is relayed in less than 90 seconds. **If you don't have the confidential hotline number, call the registry business office to get it (number below).**

### How does EMS know if there are registered children in their service area?

Registry stickers and backpack tags are EMS' cue that the child is registered. Families might also contact their area EMS to let them know when they register their child. They may bring their child by, to make the child more comfortable with the idea of EMS.



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## Information for Emergency Departments

### What is HERO Kids Registry?

HERO Kids Registry is a voluntary, no-cost system that lets any Oregon family share critical information about their child's health *before* an emergency. The information can be accessed quickly and easily by emergency medical services (EMS) and hospital emergency department (ED) providers, ensuring they have the information they need, when they need it.

### Who is HERO Kids for?

HERO Kids Registry is available to *any* Oregon child or young adult ages 0-26. The Registry is especially useful for medically complex children and young adults who experience chronic health conditions, developmental disabilities and/or mental or behavioral health conditions.

### Why should emergency departments access the Registry?

HERO Kids Registry gives EMS and ED providers a head start on understanding a child's medical history and unique needs. The Registry also provides information that can help with care or comfort.

EXAMPLES: An infant in respiratory distress has a known difficult airway. A child with fever has adrenal insufficiency and requires immediate corticosteroids. A toddler with low oxygen saturation has complex congenital heart disease.

### What information might emergency departments get from the Registry?

- Parent or legal guardian contact information
- Approach considerations
- Medical and/or behavioral conditions
- POLST information via the Oregon POLST Registry
- Emergency Protocol Letters
- Emergency Information Forms
- Alerts
- Allergies
- Medications
- Hospital preference
- Safe words

### How do emergency departments know if a child or young adult is registered?

- EMS, parent, legal guardian, or young adult provides Registry ID
- There is an Emergency Department Information Exchange (EDIE) notification
- A HERO Kids Registry ID sticker or backpack tag is visible
- ED calls the Registry hotline with a patient's basic demographic information



Example Registry ID Sticker



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## How do EDs access the Registry, and how quickly is information available?

- The Registry hotline is available 24/7. When an ED calls the hotline and provides a child's demographic information or Registry ID number, information is relayed in less than 90 seconds. **If your ED does not yet have the confidential hotline number, call the Registry business office to get it (number below).**
- Registry information is available in real time through the Emergency Department Information Exchange (EDIE).

## Who can access the HERO Kids Registry, and is it secure?

Hero Kids Registry is a secure, HIPAA-compliant database. It is operated by Registry staff trained to comply with all health privacy laws. To protect privacy and confidentiality, only the following people can access the registry:

- A parent or legal guardian who registers the child
- Young adults (aged 15-26) who register themselves
- HERO Kids Registry staff
- EMS and ED providers who are treating the child

## Who updates a child's registration?

Parents or legal guardians update their child's HERO Kids Registry information as needed. Young adults who register themselves update their own information. They are encouraged to work with their health care providers to make sure the information is accurate and complete.

## How can emergency departments encourage families to use the HERO Kids Registry?

- Offer HERO Kids brochures and flyers in the waiting room and at patient discharge. These materials can be downloaded at [www.herokidsregistry.org](http://www.herokidsregistry.org).
- Include links to HERO Kids registration in MyChart or on after-visit summaries.
- Encourage families to talk with their child's primary or specialty care providers about registering.
- Encourage young adults to talk with their providers about registering.
- Tell ED colleagues about the HERO Kids Registry.

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## Information for health care providers and other professionals

### What is HERO Kids Registry?

HERO Kids Registry is a voluntary, no-cost system that lets any Oregon family share critical information about their child's health *before* an emergency. The information can be quickly and easily accessed by emergency medical services (EMS) and hospital emergency department (ED) providers, ensuring they have the information they need when they need it.

### Who is HERO Kids for?

**HERO Kids is available to any Oregon child or young adult ages 0-26.** HERO Kids is especially useful for medically complex children and young adults who experience chronic health conditions, developmental disabilities and/or mental or behavioral health conditions.

### Why should a parent or legal guardians register their child?

In an emergency, every moment counts. By registering with HERO Kids families give EMS and ED providers a head start on understanding their child's medical history and unique needs. The information may help them provide care or comfort, such as flashing lights may cause seizures.

### How does it work?

1. In an emergency, the person calling 911 provides the child's HERO Kids Registry ID number, or indicates that the child is registered with HERO Kids.
2. EMS and ED providers use the child's information and/or Registry ID number to access key health information through a confidential provider line or from the Emergency Department Information Exchange (EDIE). Information is relayed by phone or secure fax in less than 90 seconds.

### Who can access the HERO Kids Registry, and is it secure?

The Registry is a secure, HIPAA-compliant database operated by HERO Kids Registry staff, who comply with all health privacy laws. To protect the privacy and confidentiality of children and young adults, only the following people can access the registry:

- The parent or legal guardian who registers the child
- Young adults who register themselves
- HERO Kids Registry staff
- Oregon EMS and ED providers who are treating the child



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## How can I help families learn about HERO Kids Registry?

- Offer HERO Kids brochures and flyers during visits, meetings, and appointments
- Tell colleagues and staff about HERO Kids Registry
- Help families complete the online HERO Kids Registration

## How does a parent or legal guardian register their child?

1. Gather health information: diagnoses, current medications and allergies, emergency protocol letter, history of recent procedures, etc. After visit summaries can be a good source for much of this information.
2. Register online (computer or tablet only) at [www.herokidsregistry.org](http://www.herokidsregistry.org). A paper alternative is available on request ([herokids@ohsu.edu](mailto:herokids@ohsu.edu)).
3. HERO Kids Registry staff activate the registration. If there is a problem, they will contact the parent or legal guardian.
4. A few weeks after registering online, the family gets a confirmation packet in the mail with a welcome letter, Registry ID stickers and a backpack tag with the HERO Kid Registry ID number on it.

NOTE: Young adults aged 15-26 years can register themselves.

## Some children have complex health records. Can health care providers create or update the registration?

Only parents, legal guardians, and young adults aged 15-26 can create or change a registration. They are encouraged to work with health care providers to make sure the information is accurate and complete.

## Who updates or cancels HERO Kids registration?

Only parents, legal guardians, and young adults who register themselves can update or cancel registration. They get instructions on how to update or cancel when they register. They can contact the Registry business office with any questions. They are encouraged to work with their health care providers to make sure updates are accurate and complete.

## Does HERO Kids train EMS on how to manage complex medical or behavioral health needs?

HERO Kids does not offer training or guidance to EMS on managing complex medical or behavioral health needs in an emergency. The Registry provides health information, so that EMS and ED providers can give better-informed care to registered children or young adults.

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