



Inaugural Report

Sept 2022 – December 2023

HERO Kids Registry

Oregon Center for Children and Youth with Special Health Needs (OCCYSHN)



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MESSAGE FROM THE DIRECTOR

We are thrilled to share with you the inaugural HERO Kids Registry report. Since its inception in 2019, and subsequent statewide launch in 2022, our goal has been to help ensure that children and young adults in Oregon get the highest quality care from first responders and emergency department providers.

This report describes HERO Kids' development and implementation and highlights the registry's impact. Simply put, HERO Kids has been a tremendous success. It has become a critical part of the emergency care safety net, and it is garnering national attention.

As we look to the future, we anticipate growing and evolving in response to the needs of the emergency medical care providers who care for our kids, and the families and communities with whom we partner.



Dr. Ben Hoffman
OCCYSHN Director

INTRODUCTION

Background

The Health Emergency Ready Oregon (HERO) Kids Registry is housed at Oregon Health & Science University (OHSU) and operated by OHSU staff. The registry is available to **all** children and young adults (aged 0-26) who reside in the state of Oregon. Children and young adults do not need to be OHSU patients to register with HERO Kids Registry. All Oregon emergency medical services (EMS) and emergency department (ED) providers have access to the registry.

HERO Kids Registry is funded and administered by the Oregon Center for Children and Youth with Special Health Needs (OCCYSHN), which is a statewide public health agency funded by the US Maternal and Child Health Bureau. OCCYSHN partners closely with Oregon Emergency Medical Services for Children (EMSC) Program and Oregon Family-to-Family Health Information Center (F2F). These partner organizations helped develop the registry, and they actively participate in managing and promoting it.

Population Impact

Pediatric emergencies can happen anywhere and at any time. They may occur at school, daycare, respite care, or while spending time with friends. Over 826,000 children ages 0 through 17 years old live in Oregon (Portland State University Population Research Center, 2022). In 2021, 16,247 children in this age group experienced a medical emergency requiring a call to Emergency Medical Services (Oregon Health Authority, 2022). Pediatric emergencies are different than those involving adult patients. They can be especially traumatic for the patient, their family or legal guardian, and for EMS and ED providers. In addition:

- Pediatric emergency calls are not as frequent as calls for adults, and often the emergencies are more acute.
- During pediatric calls, EMS providers must treat the patient and communicate with their parent or other adult(s) present on-scene.
- The adults on-scene may be calm, or they may be emotionally charged, increasing the emergency's complexity.
- The psychological impacts of caring for children in emergency situations can be significant; responders may be traumatized by the injury or death of a child (OHA Representative, personal email communication, March 31, 2021).

The mission of HERO Kids Registry is to provide critical health information to EMS and ED providers when they need it most so they can provide more informed care or comfort, thus reducing trauma experienced by patients, families, and providers.

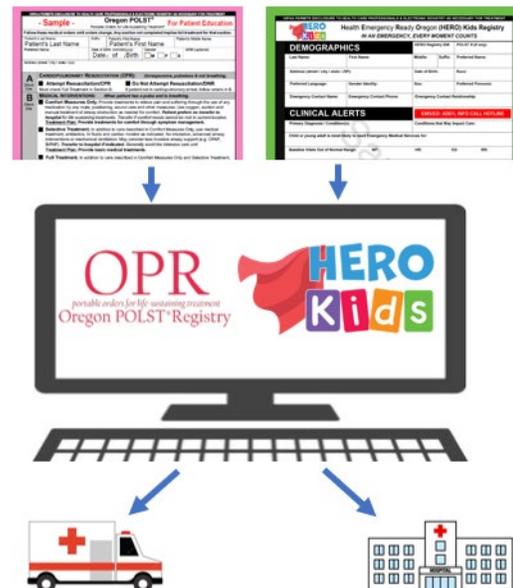
History and Development

In 2014, the Oregon EMSC Program recruited Tamara Bakewell, Oregon F2F Director and Family Involvement Manager at OCCYSHN, to become the Family Representative for the Oregon EMSC Advisory Committee. This created new connections with the Oregon EMSC Program, and over the years a strong foundation was built through collaboration around mutual goals.

In 2019, Tamara Bakewell and Rachel Ford, Oregon EMSC Program Manager, attended the EMS for Children All Grantee Meeting. During the meeting they learned about the Special Needs Tracking and Awareness Response System (STARS) out of Cardinal Glennon Children’s Hospital and thought, “*Why not do something like that in Oregon?*”. The idea for the Health Emergency Ready Oregon (HERO) Kids Registry was born, and following the presentation a team was assembled, a business plan was written, and over 20 letters of support were gathered. Title V then provided seed funding necessary to start the program.

From late 2019 through 2020, the team held listening sessions with EMS and ED providers, families, young adults, and other community partners. In 2021, these sessions evolved into workgroups that guided every aspect of the development of the HERO Kids Registry platform, paper registration form, educational materials, and videos.

The technology and workflow were built using the same infrastructure as the Oregon Portable Orders for Life Sustaining Treatment (POLST) Registry. This allowed the HERO Kids team to save both time and money. Summer 2021 to fall 2022, the HERO Kids Registry platform was built. Without the existing POLST infrastructure and a workflow that EMS and ED providers were familiar with, HERO Kids would have required additional funding and time to educate providers.



The HERO Kids Registry was open to children and young adults on September 1, 2022 and was launched for EMS and ED use on October 3, 2022.

The HERO Kids Registry is funded by Title V and managed by OCCYSHN with staff support from the Oregon EMSC Program and Oregon F2F. Business office operations are managed by the Oregon POLST Registry.

HOW THE REGISTRY WORKS

From the Family Perspective

To register, parents, legal guardians, and young adults visit the HERO Kids website and complete the online registration form. If they do not have access to a computer, a paper form is available. In a few weeks, they receive a confirmation letter, backpack tag, and set of stickers with their registry ID number. Families are advised to place the stickers on items regularly with the child or young adult and share with others such as teachers, childcare providers, etc. These items help alert EMS and ED providers that a child or young adult has information in the registry.



With a HERO Kids Registry in place, EMS would have had all the information they needed about me and my condition before they showed up. They would have been better prepared to quickly assess me, get me pain relief, and transport me to the hospital. As a person with a disability you cannot see, this registry is very important to me. – Trinity R.

Behind the Scenes

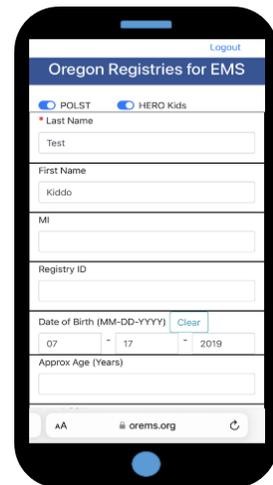
The completed forms are reviewed by HIPAA trained HERO Kids Registry staff and are activated in the HERO Kids system, making the information searchable by EMS and ED providers while providing emergency medical care. HERO Kids Registry staff also prepare confirmation letters and respond to questions and materials requests from the public.

From the EMS and ED Perspective

When EMS and ED providers are treating patients ages 0-26, they can access the HERO Kids Registry so that it becomes a part of routine emergency medical care. Providers may also see a registry ID sticker, backpack tag, or be told that the child or young adult is in the registry. To access the registry, EMS and ED providers call the confidential provider hotline or use the Oregon Registries for EMS (OREMS) app. Additionally, ED providers may receive an Emergency Department Information Exchange alert and access the information through the Collective Medical portal. The information held within the HERO Kids Registry can help provide more informed care or comfort.

"For emergency responders, especially transporting ambulance providers, having access to patient history is vital to providing timely, quality, and compassionate patient-centered care. It helps providers make informed decisions in critical moments. HERO Kids has the potential to improve the health and safety of children with medical conditions."

*- Matt Philbrick, Oregon EMSC Advisory Committee
Chairperson and Paramedic*



YEAR IN REVIEW

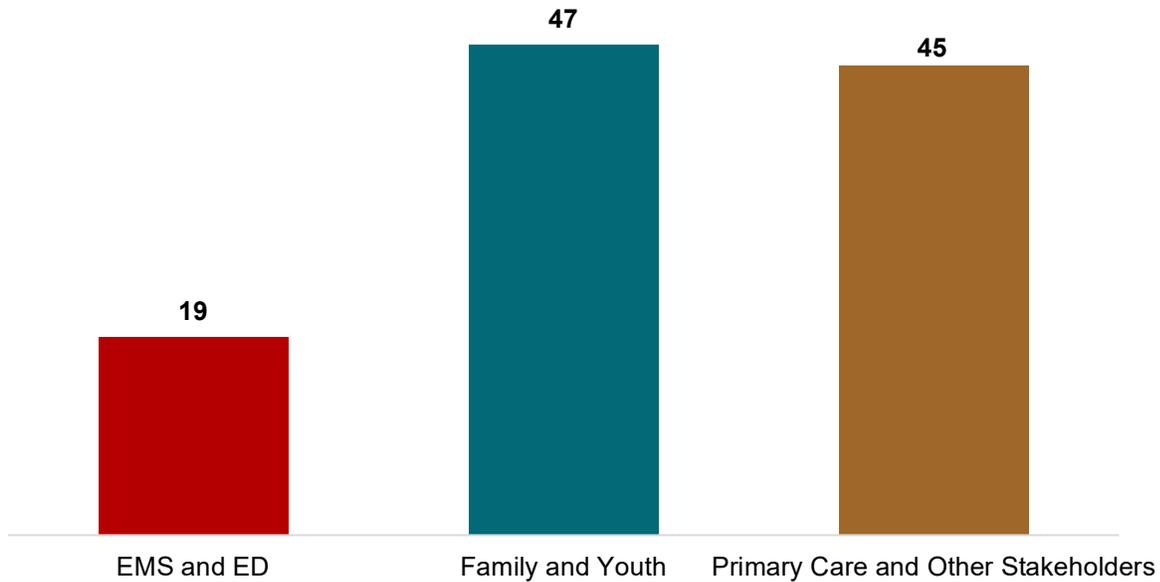
Education and Outreach

Education is foundational to the success of any statewide program. A primary goal was to increase awareness and understanding of the HERO Kids Registry. To accomplish this, the HERO Kids team developed and enacted a robust education plan. Results of those efforts are detailed below.

Presentations and Conferences

Between 8/1/2022 and 12/31/2023 the HERO Kids Registry team completed 111 education outreach opportunities including presentations, conferences, and community events. Educational efforts focused on three groups: EMS and ED providers; families and youth; and primary care providers and other stakeholders.

Presentations and Conferences, 8/1/2022-12/31/2023



Print and Media

HERO Kids was featured in many community and professional organization newsletters and announcements. A sampling is listed below. Additionally, HERO Kids was featured on-air by [KGW's Healthier Together](#) and online by [KOIN's Health News](#).

Mentions and Pages:

- [Bend School District newsletter](#)
- [Hood River County School District PeachJar page](#)
- [Malheur County Health Department page](#)
- [Oregon Health News](#)
- [Oregon Nurse Home Visiting newsletter](#)
- [Open Oregon Educational Resources EMS Lab Manual](#)
- [Provider Matters newsletter](#)
- [Siletz Valley Fire page](#)
- [Siuslaw School District page](#)
- [University Center for Excellence in Developmental Disabilities X post](#)

Marketing Video Development

In spring 2023, the HERO Kids team worked with the federally funded Pediatric Pandemic Network to create three marketing videos. Each video briefly describes a different use and benefit of HERO Kids: *Everyday Emergencies*; *Behavioral Health*; and *Disaster Preparedness*. The one-minute videos were disseminated via social media, websites, and other video platforms.

Click the images to watch:



Everyday Emergencies



Behavioral Health



Disaster Preparedness

Social Media

HERO Kids has run social media campaigns since the launch of the program in 2022. These campaigns have reached over one million people. In addition to the social media campaigns, the HERO Kids team provides social media kits upon request. The kits include suggested text, images and logo files, and MP4 videos.

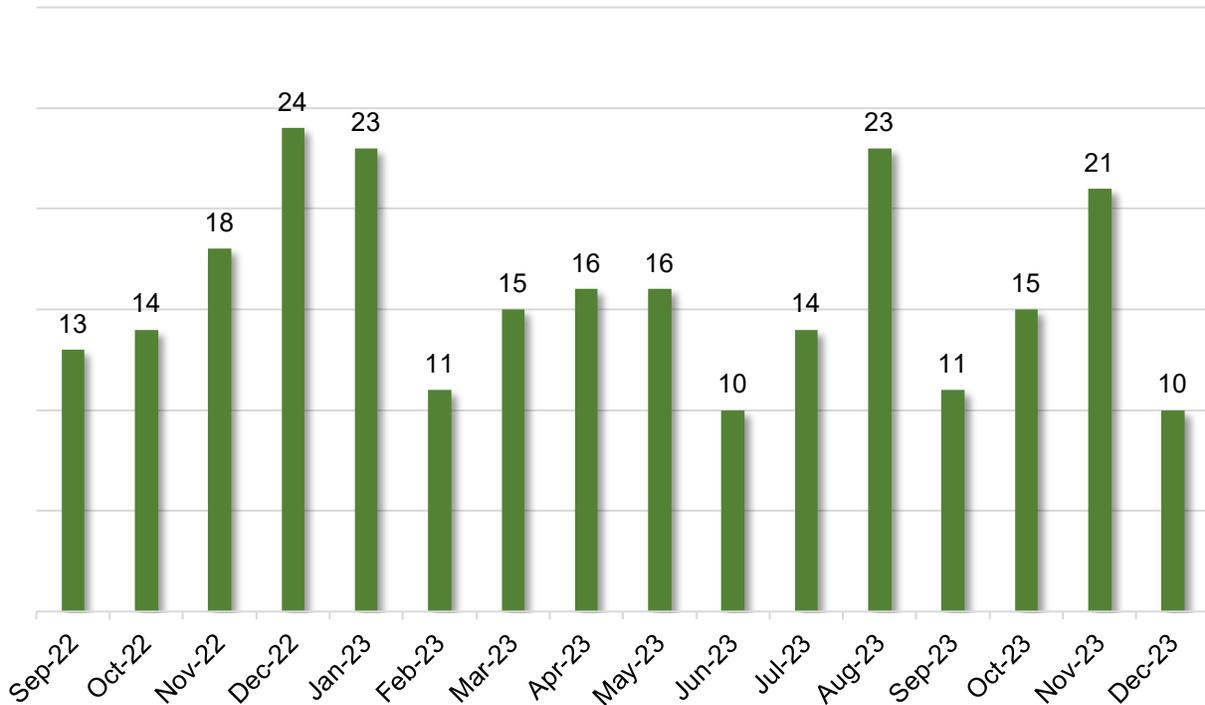
	Original Campaign	New Campaign (2023 Marketing Videos)
Date Range	10/2022-10/2023	11/2023-ongoing
Platforms	Facebook, Instagram	Facebook, Instagram, X
Geographic Area	Oregon	Oregon
Age	18-65+	18-65+
Interest Groups	Families, Professionals	Families, Professionals
Views	724,274	314,314 (11/2023-12/31/2023)
Examples		

Aggregate Registrant Data

New Registrants

Between September 1, 2022 and December 31, 2023 **254** children and young adults enrolled into the HERO Kids Registry.

HERO Kids Registrants
9/1/2022-12/31/2023



Registrant Age

HERO Kids Registry is for children and young adults aged 0 – 26 years. As of December 31, 2023, the average age of all registrants was 9.66 years old. The youngest registrant was 0.48 years old, and the oldest was 24.99 years old.

Languages

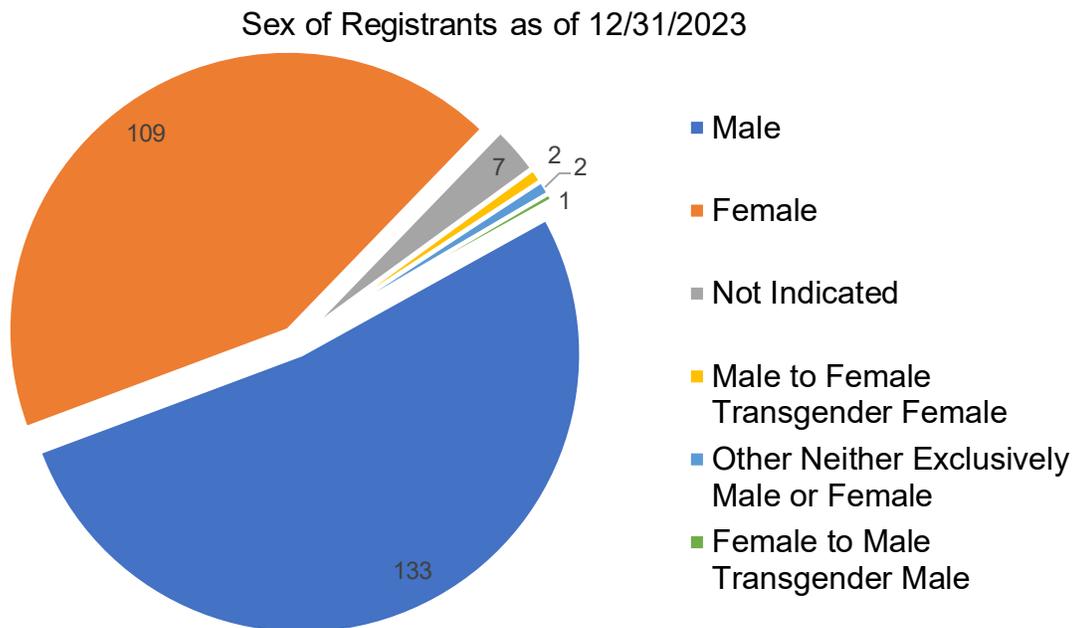
Registrants have the option to note their preferred languages. Between September 1, 2022 and December 31, 2023 **eight** different languages were noted.

Registrant Preferred Language (if indicated) 9/1/2022-12/31/2023	
English	255
Spanish	4
Other	1

Second or Other Language (if indicated) 9/1/2022-12/31/2023	
Spanish	7
ASL	6
Nonverbal	5
Arabic	1
Augmented and Alternative Communication (AAC)	1
Picture Exchange Communication System (PECS)	1
Protactile	1
Somali	1

Sex of Registrant

Of the 254 registrants, 52.36% are male, 42.91% are female, 2.75% did not indicate sex, 0.79% are transgender female, 0.79% indicated other neither exclusively male or female, and 0.4% are transgender male.

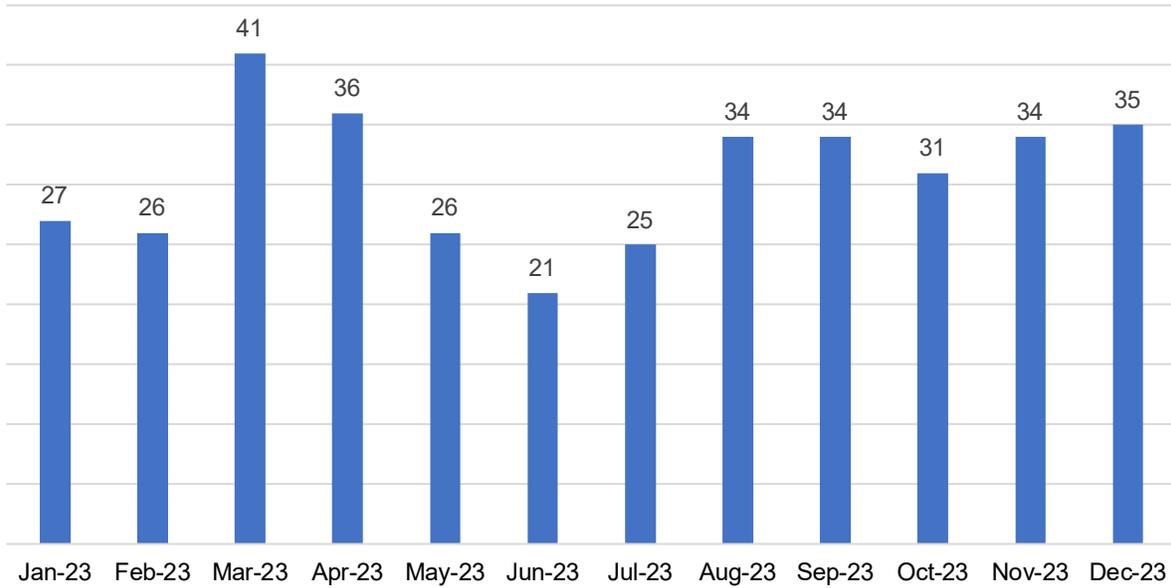


Registry Utilization

Confidential Provider Hotline Calls by Month

The confidential provider hotline is available 24/7. The hotline launched October 3, 2022. However, call data was not captured until January 1, 2023. Between January 1, 2023 and December 31, 2023 370 calls were received.

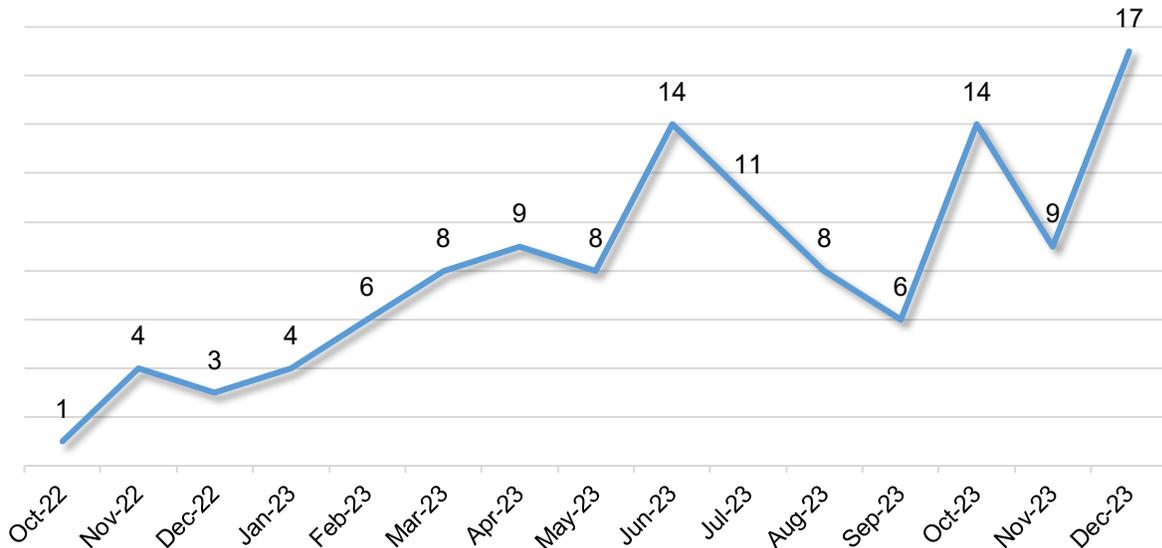
Confidential Provider Hotline Calls
1/1/2023-12/31/2023



Emergency Department Information Exchange (EDIE) Alerts

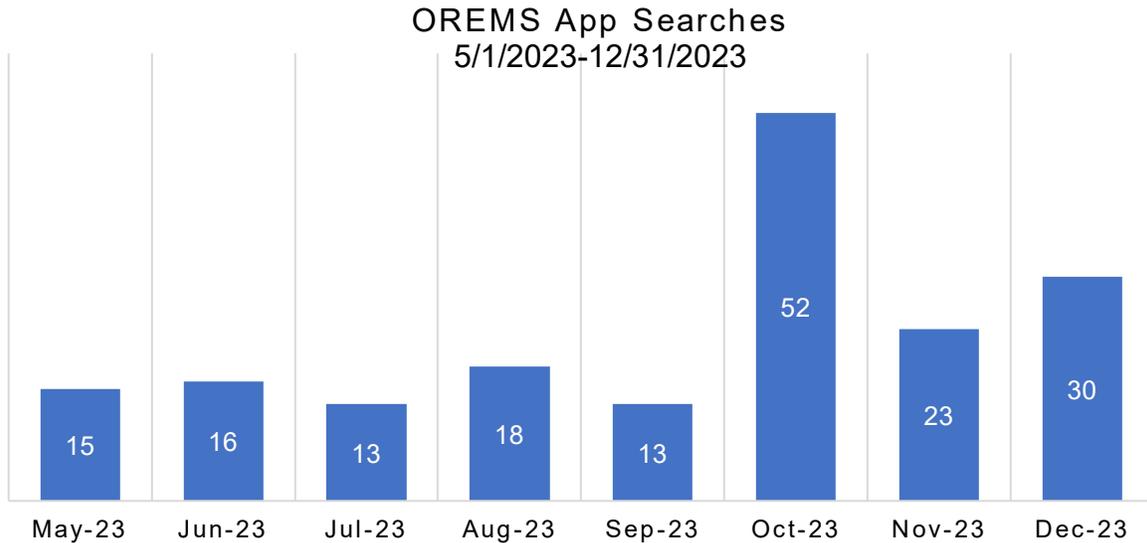
Oregon’s Emergency Department Information Exchange (EDIE) generates an alert for providers whenever a patient matches a registrant in the HERO Kids Registry. EDIE alerts are available at all Oregon emergency departments. EDIE alerts vary by hospital and may show up in the ED patient track board, electronic health record system, or by fax. Between October 1, 2023 and December 31, 2023 **122** alerts were generated.

Emergency Department Information Exchange (EDIE) Alerts
10/1/2022-12/31/2023



Oregon Registries for EMS (OREMS) App Searches

Between May 1, 2023 and December 31, 2023, a total of **180** searches were conducted by emergency responders checking for registry information. As of 12/31/2023, **65** EMS agencies and **4** hospital EDs across Oregon have enrolled to use the Oregon Registries for EMS (OREMS) app.



Heat Map

Registrants by County

HERO Kids registrants reside in 23 of 36 Oregon counties. Two of 23 counties are frontier (denoted with a *) and 21 of 23 counties are rural. All urban centers are represented.

