



# HERO Kids Registry

An Innovative Program Filling the EMS and ED Information Gap  
Through Partnership

May 14, 2026

---

PRESENTED BY:

Tamara Bakewell, EMSC FAN, OCCYSHN Family Involvement Coordinator

Rachel Ford, Oregon EMSC Program Manager

Brittany Tagliaferro-Lucas, HERO Kids Registry Program Manager, OCCYSHN Program Administrator

# Presenters



**Tamara Bakewell, MA**

**Family Involvement Coordinator, Oregon Center for Children and Youth with Special Health Needs (OCCYSHN)**

Ms. Bakewell has worked in the field of family support and advocacy since 1990, following the birth of her oldest child who experienced special health needs. As OCCYSHN's Family Involvement Coordinator, she provides technical assistance around family experiences and family leadership to all Title V initiatives and programs for children and youth with special health needs (CYSHCN).



**Rachel Ford, MPH**

**Oregon EMSC Program Manager, Oregon Health Authority**

Rachel is the Emergency Medical Services for Children Program Manager for the Oregon Health Authority. Rachel earned her bachelor's degree in Psychology and Business Administration from University of Oregon and her master's degree in Public Health Management and Policy from Portland State University. Rachel has 15 years of public health experience, including tribal public health, hospital system accreditation and compliance, hospital and clinic project management, and state government service.



**Brittany Tagliaferro Lucas, BS**

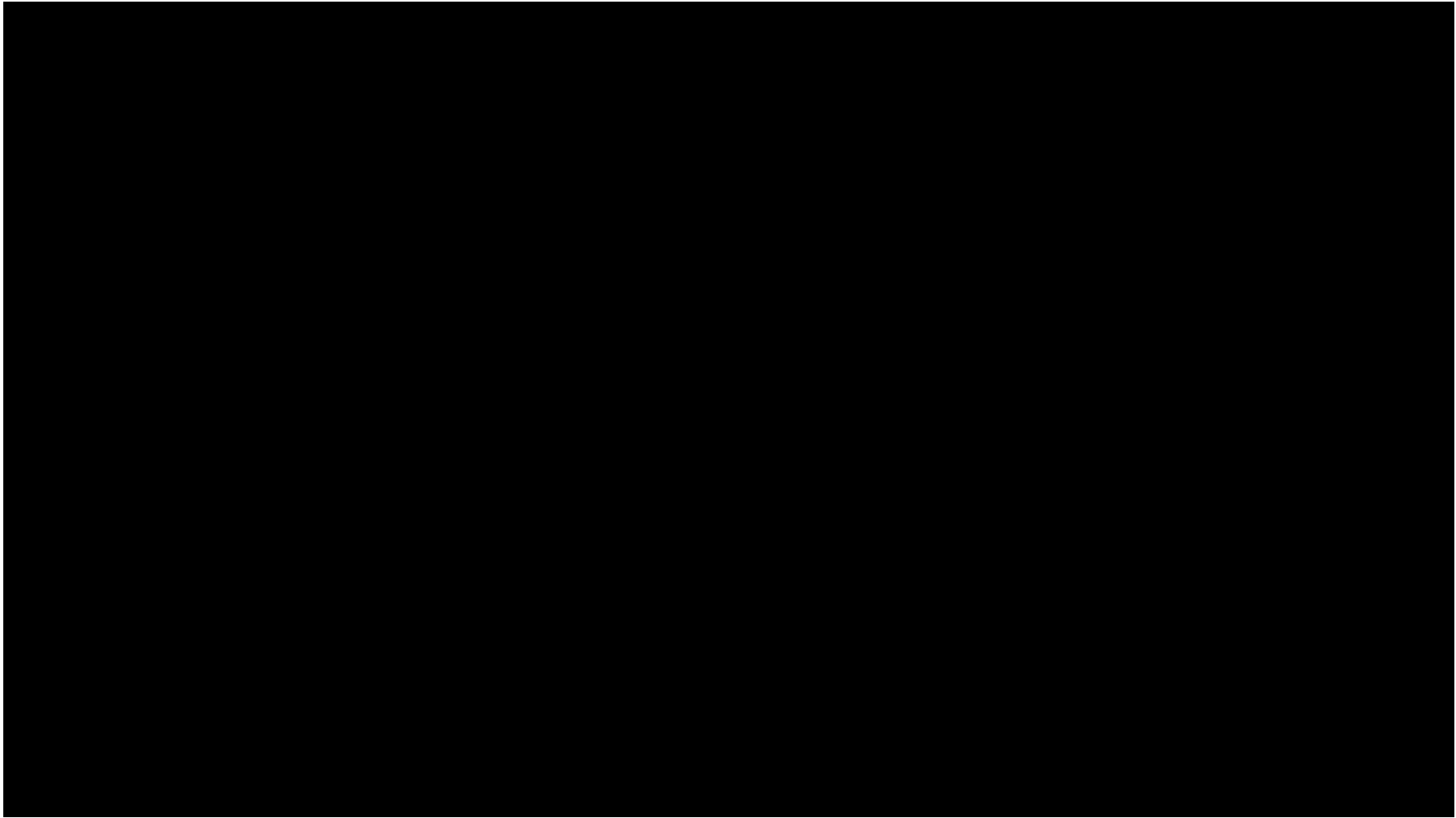
**Program Administrator and HERO Kids Registry Program Manager, OCCYSHN**

Brittany is the Program Administrator for the Oregon Center for Children and Youth with Special Health Needs and HERO Kids Registry Project Manager. Brittany has 13 years of experience managing statewide programs and registries. She was a founding member of the Oregon Portable Orders for Life Sustaining Treatment (POLST) Registry and remains active in the POLST community as a consultant to the Oregon POLST Coalition.



- HERO Kids Registry Overview
- Partnership and Development
- Funding, Marketing and Data
- Questions

# What is the Health Emergency Ready Oregon (HERO) Kids Registry?

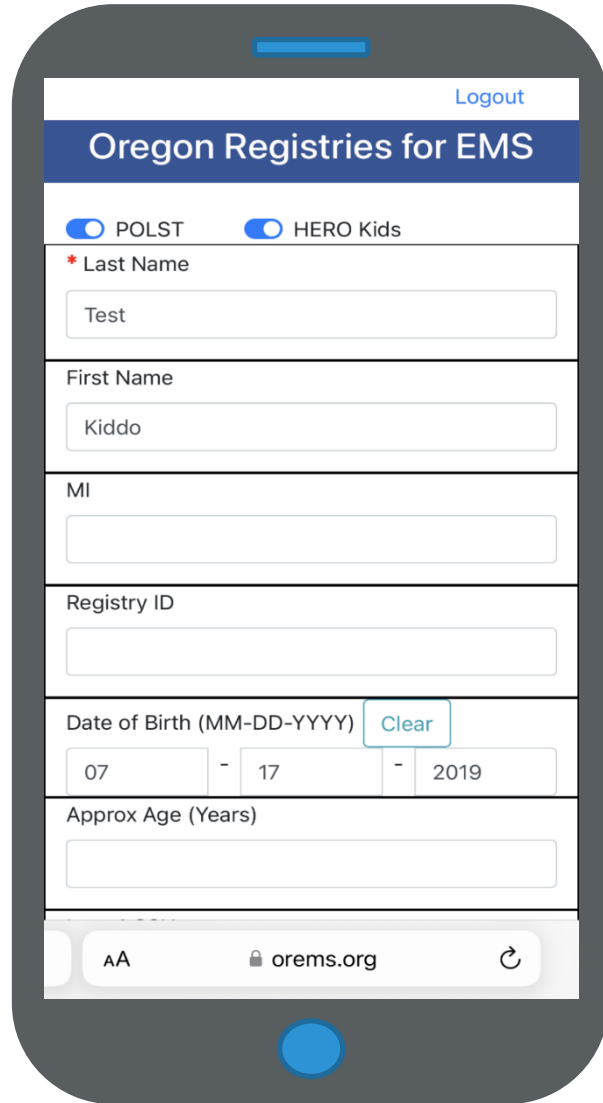




# Who is HERO Kids for?

- Any Oregon child or young adult up through age 26
- Especially useful for young people with:
  - complicated or chronic health conditions
  - developmental disabilities
  - mental health conditions

# How does the Registry work?



The screenshot shows a mobile application interface for "Oregon Registries for EMS". At the top right is a "Logout" link. Below the title bar are two toggle switches: "POLST" and "HERO Kids", both of which are turned on. The form contains several input fields: "Last Name" (with a red asterisk) containing "Test", "First Name" containing "Kiddo", "MI" (empty), "Registry ID" (empty), "Date of Birth (MM-DD-YYYY)" with a "Clear" button and values "07", "17", and "2019", and "Approx Age (Years)" (empty). The bottom of the screen shows a browser address bar with "orems.org" and a refresh icon.

**In an emergency:** Person calls 911 and gives the dispatcher HERO Kids Registry ID number, or tells EMS providers the child or young adult is registered

Once EMS and ED providers know a child or young adult is registered **or** have enough information to identify:

- Call confidential provider line
- Use the Oregon Registries for EMS (OREMS) app
- Receive Emergency Department Information Exchange (EDIE) alert → call confidential provider line **or** view Collective Medical Portal

Information is available in fewer than 90 seconds.

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

Hero Kids Registry is secure and HIPAA compliant. It is operated by Registry staff trained to comply with all health privacy laws. Registry privacy and confidentiality is protected by only allowing the following people to access:



- The parent or legal guardian who registers their child or young adult
- The young adult who self registers
- HERO Kids Registry staff
- EMS and ED providers who are treating the child or young adult

# How families register with HERO Kids

- Register online with computer or tablet at [www.herokidsregistry.org](http://www.herokidsregistry.org) and use the Registration Guide
- Registration takes 15-60 minutes
- Provider-signed Oregon Health Emergency Protocol or Emergency Information Form may be included
- Families receive welcome letter, stickers, and backpack tag with the HERO Kids Registry ID number



# What information can be entered into the Registry?

- Allergies and medications
- Factors that may impact care
- Medical and/or behavioral conditions
- Medical equipment or technology
- Oregon Health Emergency Protocol or Emergency Information Form
- Parent or legal guardian contact information
- What EMS may observe

### Alerts and Instructions

Child or young adult is most likely to need emergency medical services for:

Does the child or young adult have a POLST form in the Oregon POLST Registry?

Y  N

EMS may observe the following:

Make a selection by pressing the + button and check all that apply

+

Comfort items (if applicable)  
(Examples: favorite stuffed animal or blanket)

Safe word or phrase (if applicable)

Factors or conditions that may impact care

Make a selection by pressing the + button and check all that apply

+

### Please Make a Selection

Filter Results

- Avoids eye contact
- Avoids or fears people with uniforms or badges
- Does not/cannot respond to instruction or commands
- Does not/cannot use spoken language
- Easily fatigued/low stamina
- Highly sensitive to lights, sounds, or smells

“EMS may observe” dropdown



# Oregon Health Emergency Protocol Form

Oregon Health Emergency Protocol Form provides standardized information and format.

**MD, DO, NP, PA, or ND includes:**

- Patient (child or adult) information
- Emergency Management Recommendations
- Emergency consult phone number
- Attestation

**Endorsed by:**

- Oregon Chapter of the American College of Emergency Physicians
- Oregon Emergency Nurses Association

**Available online:** <https://tinyurl.com/emprot>

HIPAA PERMITS DISCLOSURE TO HEALTH CARE PROFESSIONALS & ELECTRONIC REGISTRY AS NECESSARY FOR TREATMENT

## Oregon Health Emergency Protocol

Patient's Last Name:	Suffix:	Patient's First Name:	Patient's Middle Name:
Date of Birth: (mm/dd/yyyy): _/_/		Pronouns:	Address (street/city/zip):

**HEALTH EMERGENCY MANAGEMENT RECOMMENDATIONS:**

*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.*

**ATTESTATION of MD/DO/NP/PA/ND (REQUIRED)**

*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.*

MD/DO/NP/PA/ND Printed Name: <b>required</b>	Signer's Phone Number:	Consult Phone Number:
MD/DO/NP/PA/ND Signature: <b>required</b>	Date Signed: <b>required</b>	Signer's License Number:

© 2023 Oregon Health & Science University (OHSU)

# HERO Kids registration form

- Once complete, a PDF will be generated for families and young adults to print for their records.
- We recommend putting a copy on the refrigerator for EMS access and sharing a copy with caregivers and schools.



HERO Kids Health Emergency Ready Oregon (HERO) Kids Registry  
IN AN EMERGENCY, EVERY MOMENT COUNTS

DEMOGRAPHICS		HERO Registry ID#:	POLST # (if any):	
Last Name:	First Name:	Middle:	Suffix:	Preferred Name:
Address (street / city / state / ZIP):		Date of Birth:	Race:	
Preferred Language:	Gender Identity:	Sex:	Preferred Ponouns:	
Emergency Contact Name:	Emergency Contact Phone:	Emergency Contact Relationship:		

CLINICAL ALERTS		EMS/ED: ADD'L INFO CALL HOTLINE			
Primary Diagnosis / Condition(s):	Conditions that May Impact Care:				
Child or young adult is most likely to need Emergency Medical Services for:					
Baseline Vitals Out of Normal Range:	BP:	HR:	O2:	RR:	
Medication:					
Medication Allergy:					
Environmental or Food Allergy:					
Drug Use:	<input type="checkbox"/>	Alcohol:	<input type="checkbox"/>	If Yes to Use: Type?	
EMS May Observe the Following:					
Medical Equipment or Technology:					
Mobility Devices:					
Primary/Specialty Care:	Phone:	Safe Word(s):			
Name of Person to Accompany:	Relationship:	Blood Type:			
Position of Comfort If Transported:	Comfort Item(s):				
Preferred Hospital:	Reason for Choosing Hospital:				
Emergency Information Form:	<input type="checkbox"/>	Protocol Letter:	<input type="checkbox"/>	POLST Form in OPR:	<input type="checkbox"/>

Version 5/2022 • www.HeroKidsRegistry.org © 2022 Oregon Health & Science University





# HERO Kids Program Summary

- For **all** Oregon children and young adults through age 26
- HERO Kids should be integrated into routine medical care
- Portable and accessible across state
- Excellent tool for emergency preparedness and reunification

# How Partnership Built the HERO Kids Registry

# Background

- **2014:** Oregon Emergency Medical Services for Children (EMSC) recruited Family Representative from the Oregon Family to Family Health Information Center (F2F)
- **2019:** Inspiration: STARS program → Health Emergency Ready Oregon (HERO) Kids Registry
- **2019 - 2022:** Right people, right time, right infrastructure

# Partnership: EMSC, F2F and Title V

- Authentic partnership
- Inclusion at every step
- Continued commitment



# HERO Kids Advisors

Family Representatives (10)

Care Coordinators

Emergency Medicine Physicians

Emergency Medical Services (EMS)

Fire Departments

F2F

Mental and Behavioral Health Programs/Clinics

Nurses

Oregon Department of Education

Oregon EMS for Children Program

Oregon POLST Registry

Pediatric Specialty Clinics

Primary & Specialty Care Providers

Public Health

Title V

# Development process: exploration



We asked ourselves: What would HERO Kids look like? Who would it be for?

- Brainstorming and system mock-up
- Expertise from partners was key
  - Listening session 1: EMS, ED, and other professionals
  - Listening session 2: families and youth

# Development Process: Ideas to Action

## *Elements that Required Partnership*

- Write a business plan
- Gather letters of support
- Secure start up funds
- Contract for registry build and form design
- Convene advisory committee and workgroups
- Sign MOU for business operations
- Develop and deliver educational and marketing materials

# Development process: implementation timeline

- **2020-2023:** Developed educational materials
  - Info sheets, registration guide, videos, stakeholder updates, etc.
- **2022:** Developed informational website
- **September 12, 2022:** First registration
- **October 3, 2022:** Launched confidential provider line
- **October 21, 2022:** Launched Oregon Registries for EMS (OREMS) app



HEALTH EMERGENCY  
READY OREGON

With HERO Kids Registry, any Oregon family can make sure the people caring for their child in an emergency have the information they need.

- In an emergency, first responders and emergency departments can get HERO Kids Registry information in less than 90 seconds.
- Families decide what information emergency responders need (like their child's health conditions, medications, allergies, behaviors, etc.).
- HERO Kids Registry is confidential and HIPAA-compliant. The information is only shared with medical providers during an emergency.
- HERO Kids Registry is available to any Oregonian (birth through 26 years).
- HERO Kids Registry information can be updated or cancelled any time.
- There is NO COST to families for using HERO Kids Registry.

# Ongoing Partnership

- HERO Kids leadership team: EMSC, F2F and Title V
- Monthly team meetings include Registry staff
- Quarterly HERO Kids updates for Oregon EMSC Advisory Committee and stakeholders
- Co-creation of ALL materials
- Co-advisement on operational issues
- Co-delivery of ALL outreach and education

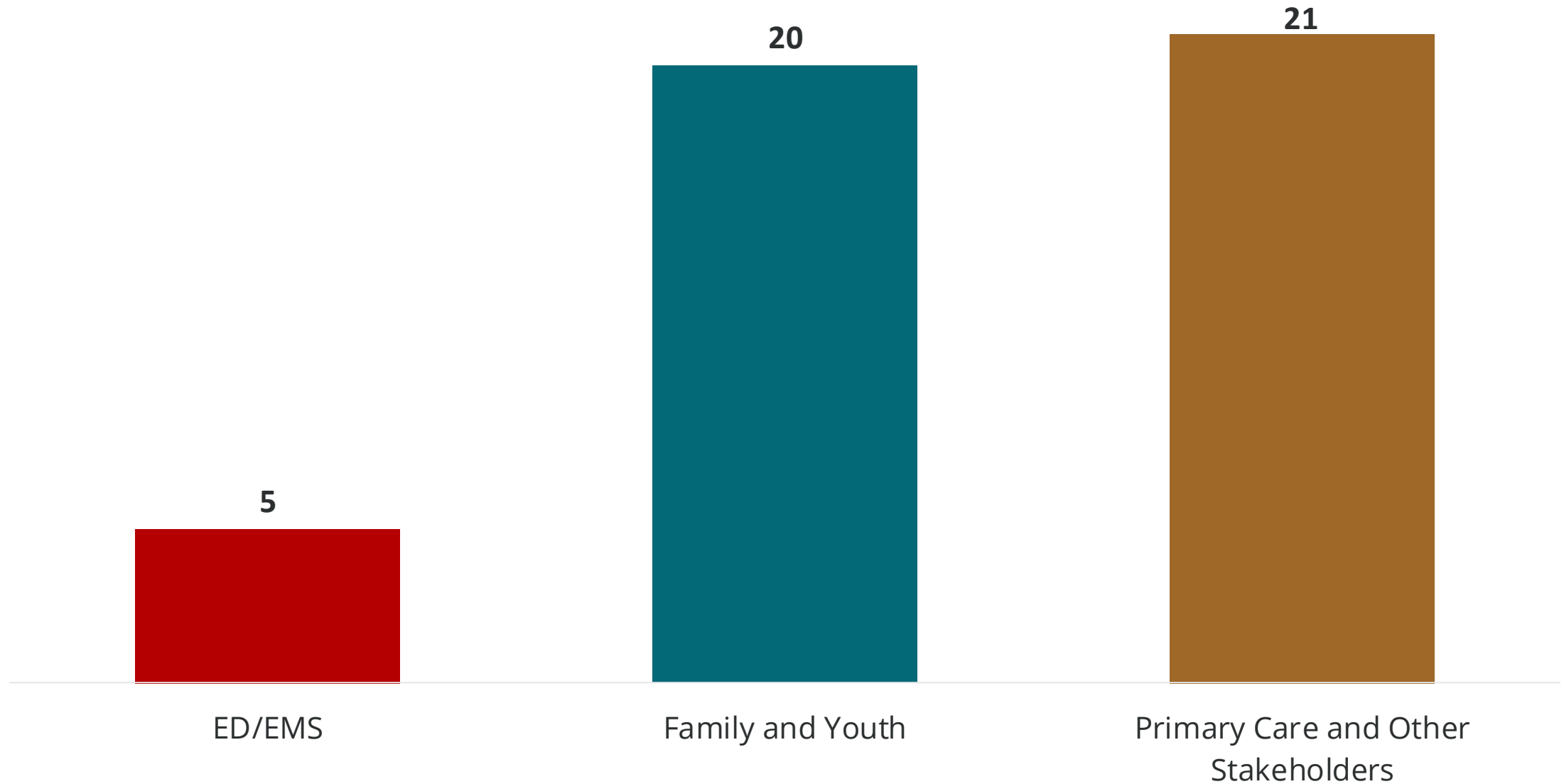
# Funding, Marketing & Data

# Funding

- **January 2020:** EMSC Innovation and Improvement Center (EIIC) Telehealth Collaborative Grant (\$50,000)
- **February 2021:** Oregon Health Security, Preparedness and Response Funds (\$20,000)
- **August 2021:** HRSA Emerging Issues Grant (\$249,841)
- **Current Operational Support:** Oregon Title V CYSHCN (\$131,297.29/yr)

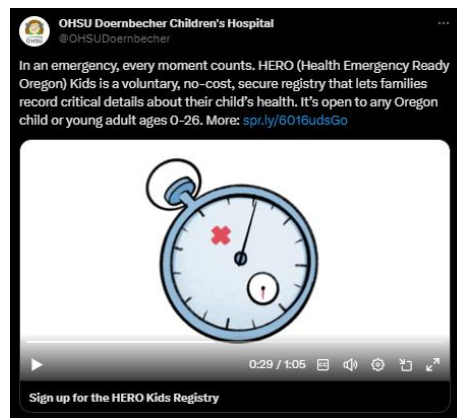
# HERO Kids Presentations in 2025

Total: 46



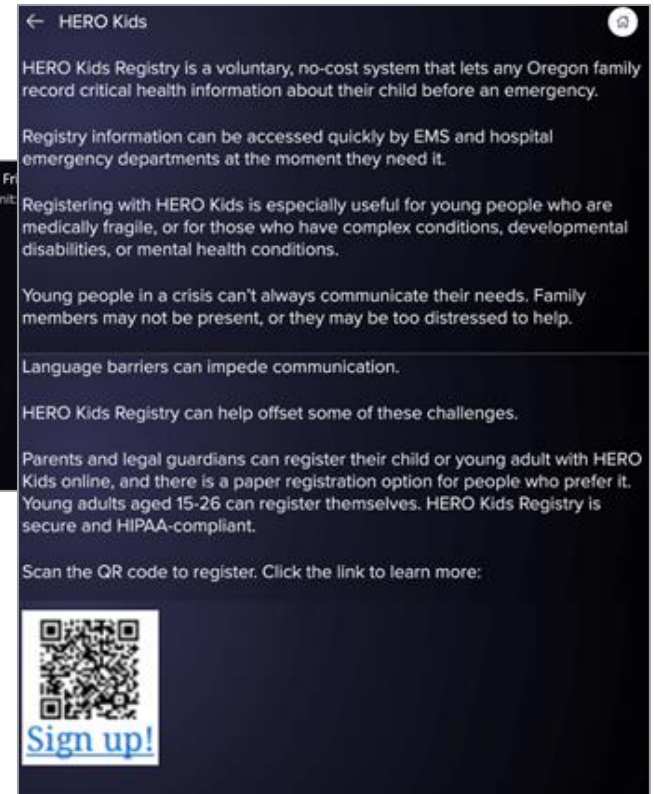
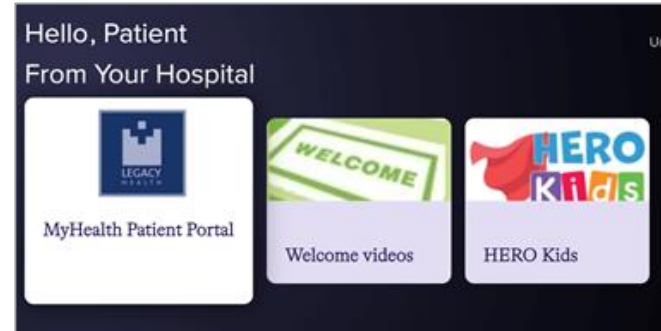
# Marketing to the public

- 2022-2025 Social Media Campaigns
- 2023 Local News Segments
- 2024 Digital and Print Billboards
- 2024 Google Ads



# In-hospital Marketing

- Patient video screens
- After-visit summaries
- EMR shortcuts (dot phrases)



**AFTER VISIT SUMMARY**  
 Stella A. Rebuild DoB: 8/16/2011 4/21/2022 OHSU Emergency Department

Thank you for entrusting your care to us. Below is a summary of your visit and future instructions.

**Instructions**  
 Stella was seen in the Emergency Department today with fever and lethargy. We found that her blood sugar was low and she needed fluids with dextrose and hydrocortisone for her adrenal insufficiency. We observed her for several hours and she is now taking good oral intake and appears near her baseline with stable blood sugars. You should encourage regular eating and drinking (preferably Pedialyte) over the next few days while she is ill. If she develops confusion, becomes more lethargic, or looks more ill, please return to the Emergency Department. Otherwise you should follow-up with your regular doctor in 1 day and follow-up with your endocrinology team.

It was a pleasure meeting you today.

Because Stella has a more complicated medical history she may benefit from a new program called HERO Kids.

Health Emergency Preparedness: HERO Kids Registry is a voluntary, no-cost system that lets any Oregon family record critical health information about their child before an emergency. Registry information can be accessed quickly by EMS and hospital emergency departments at the moment they need it. Parents and legal guardians can register their child or young adult with HERO Kids online. Young adults aged 15-26 can register themselves. Information and registration are available at [www.herokidsregistry.org](http://www.herokidsregistry.org).

**Today's Visit**  
 You were seen by Mash, Margaret  
 Reason for Visit: Abdominal pain  
 Diagnoses:  
 • Addison's disease  
 • Generalized abdominal pain

Blood Pressure 110/80	Weight 81 lb 9.1 oz (37 kg)
Height 4' 7" (1.397 m)	Temperature (Forehead) 98.8 °F
Pulse 70	Respiration 18
Oxygen Saturation 98%	

**.EDPEDSHERO**

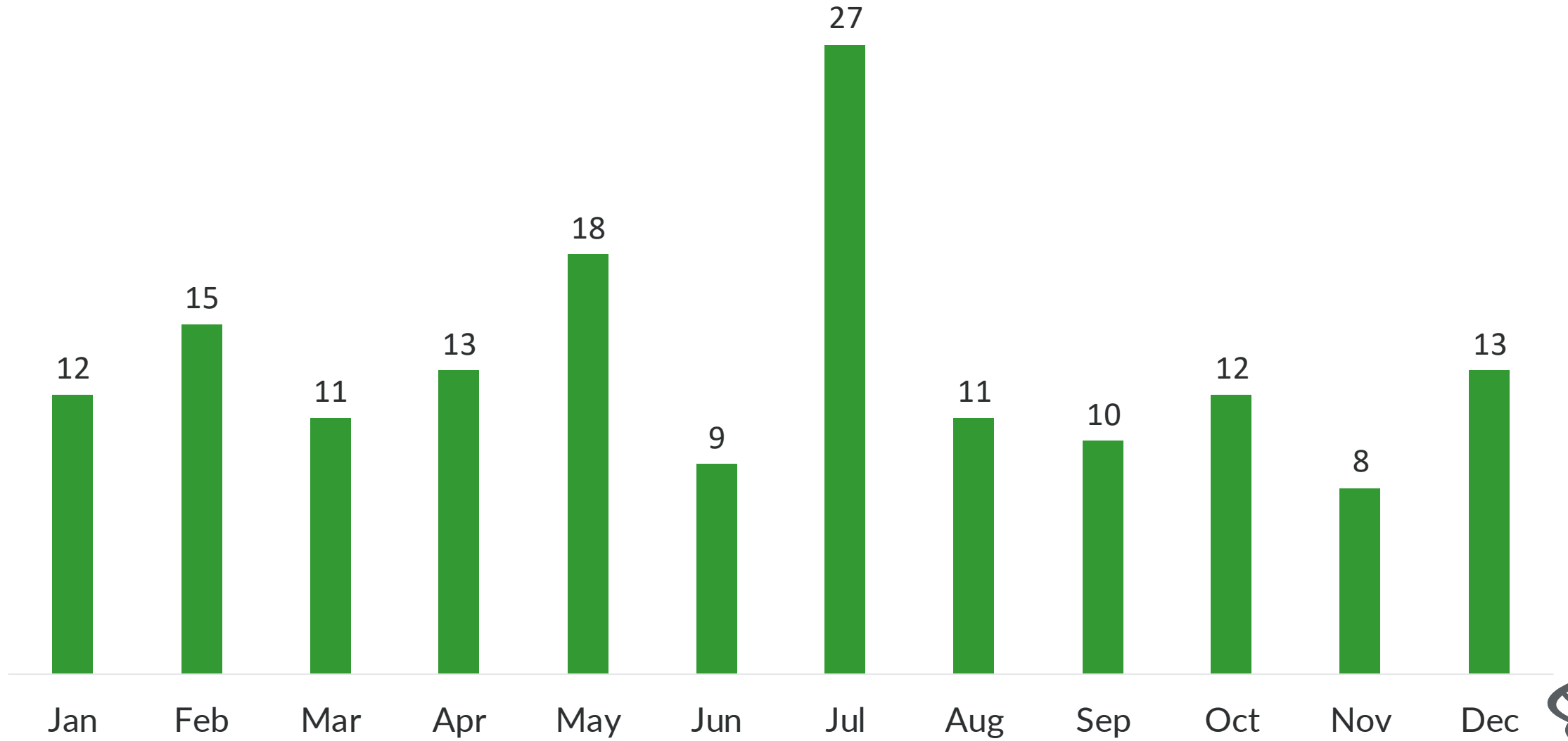
**@HEROKIDS**

**Health Emergency Preparedness: HERO Kids Registry** is a voluntary, no-cost system that lets any Oregon family record critical health information about their child *before* an emergency. Registry information can be accessed quickly by EMS and hospital emergency departments at the moment they need it. Parents and legal guardians can register their child or young adult with HERO Kids online. Young adults aged 15-26 can register themselves. Information and registration are available at [www.herokidsregistry.org](http://www.herokidsregistry.org).



# HERO Kids Registrations Received in 2025

Total: 159



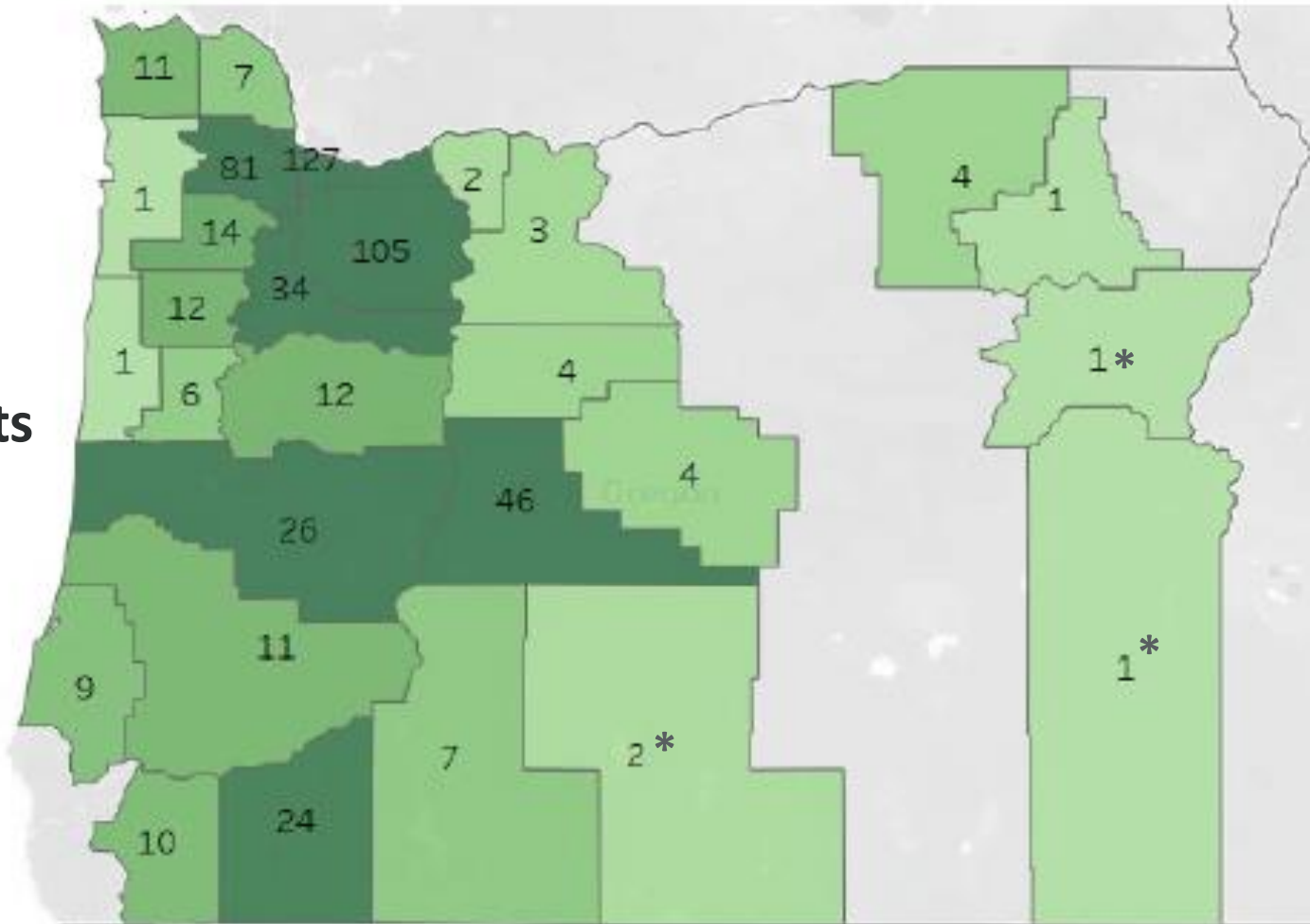
# Registration by County as of Dec 31, 2025

- **Registrants reside in 28 of 36 counties**

- 3 of 28 are Frontier\*
- 25 of 28 are Rural
- Includes all Urban Areas

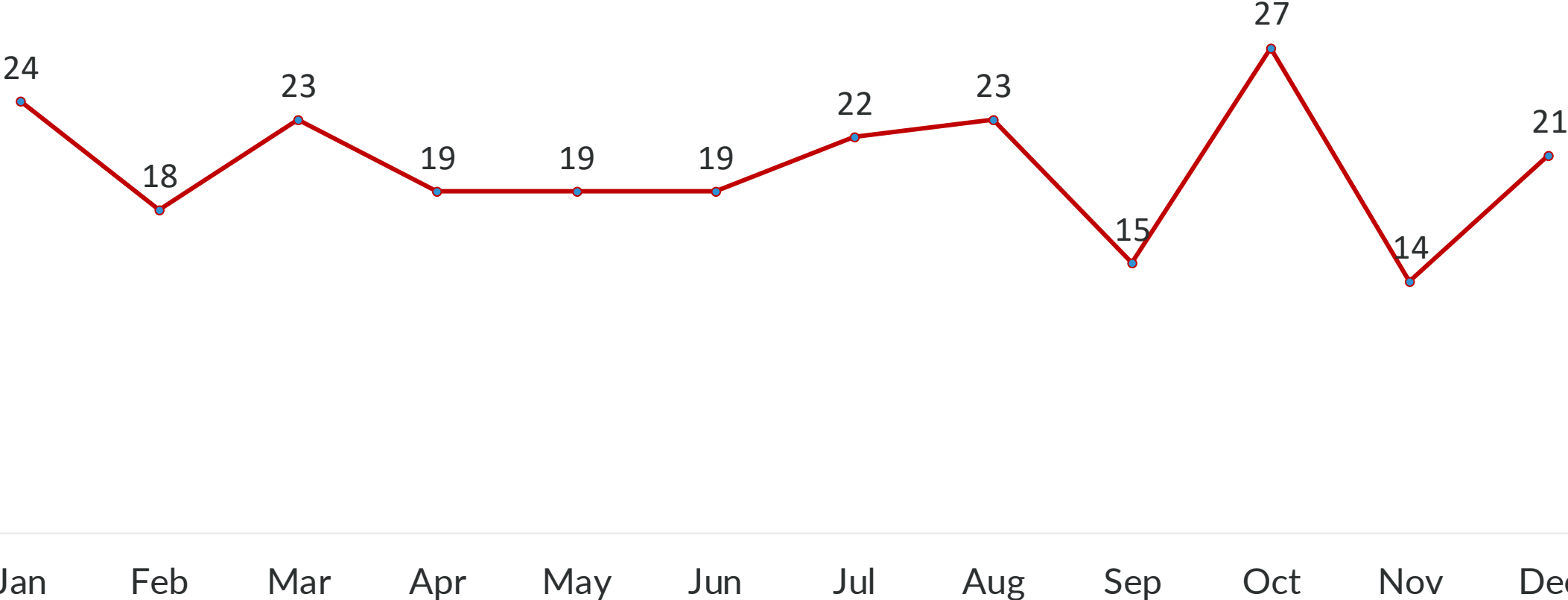
- **Counties without registrants**

- Curry
- Gilliam
- Grant
- Harney
- Morrow
- Sherman
- Wallowa
- Wheeler



# Emergency Department Information Exchange (EDIE) Alerts Received in 2025

Total: 244

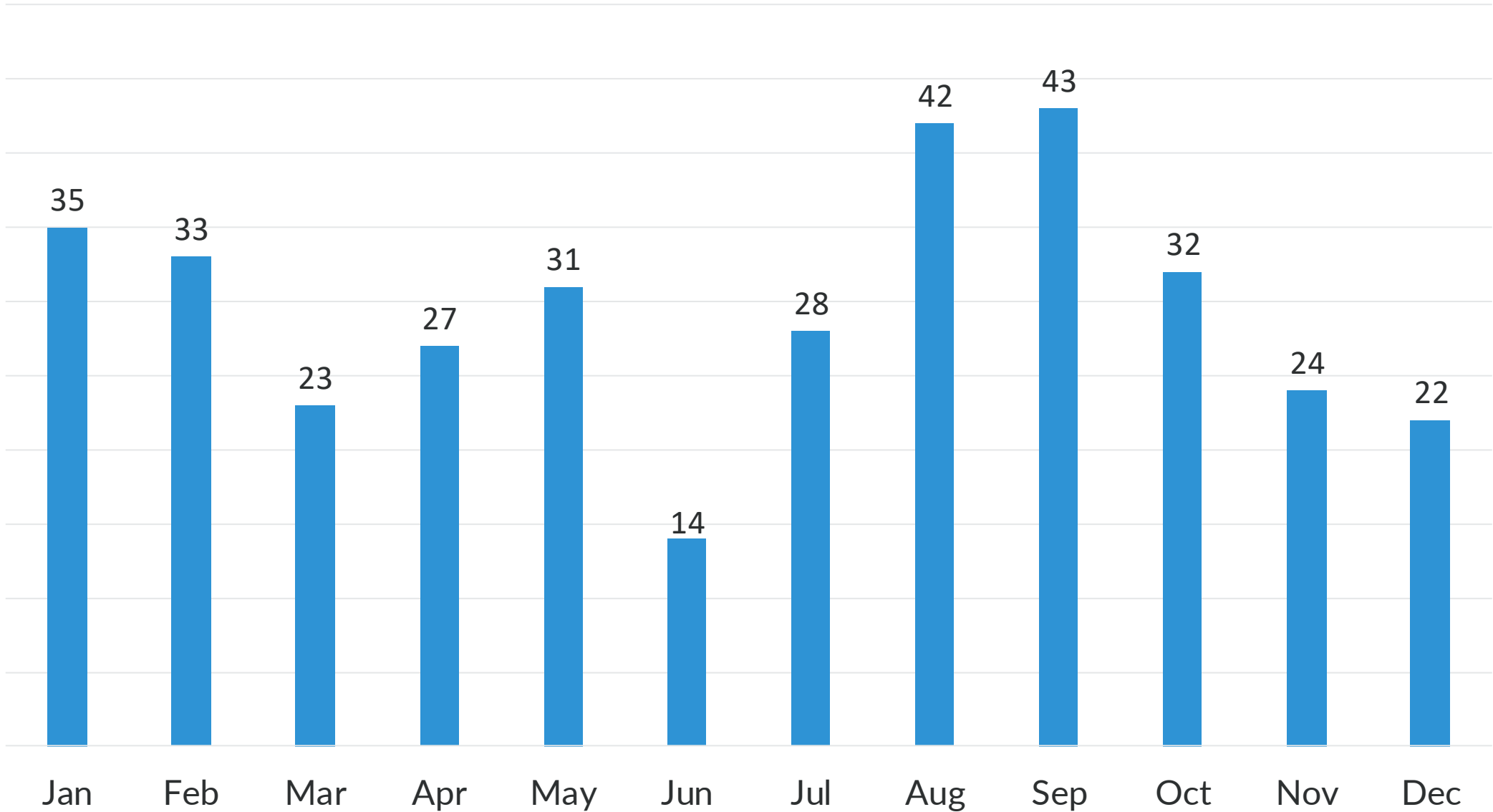


\*An EDIE alert is a notification that tells Emergency Department providers that the child or young adult has information in the HERO Kids Registry. EDIE alerts show up in the ED track board, EHR, or by fax depending on the hospital.

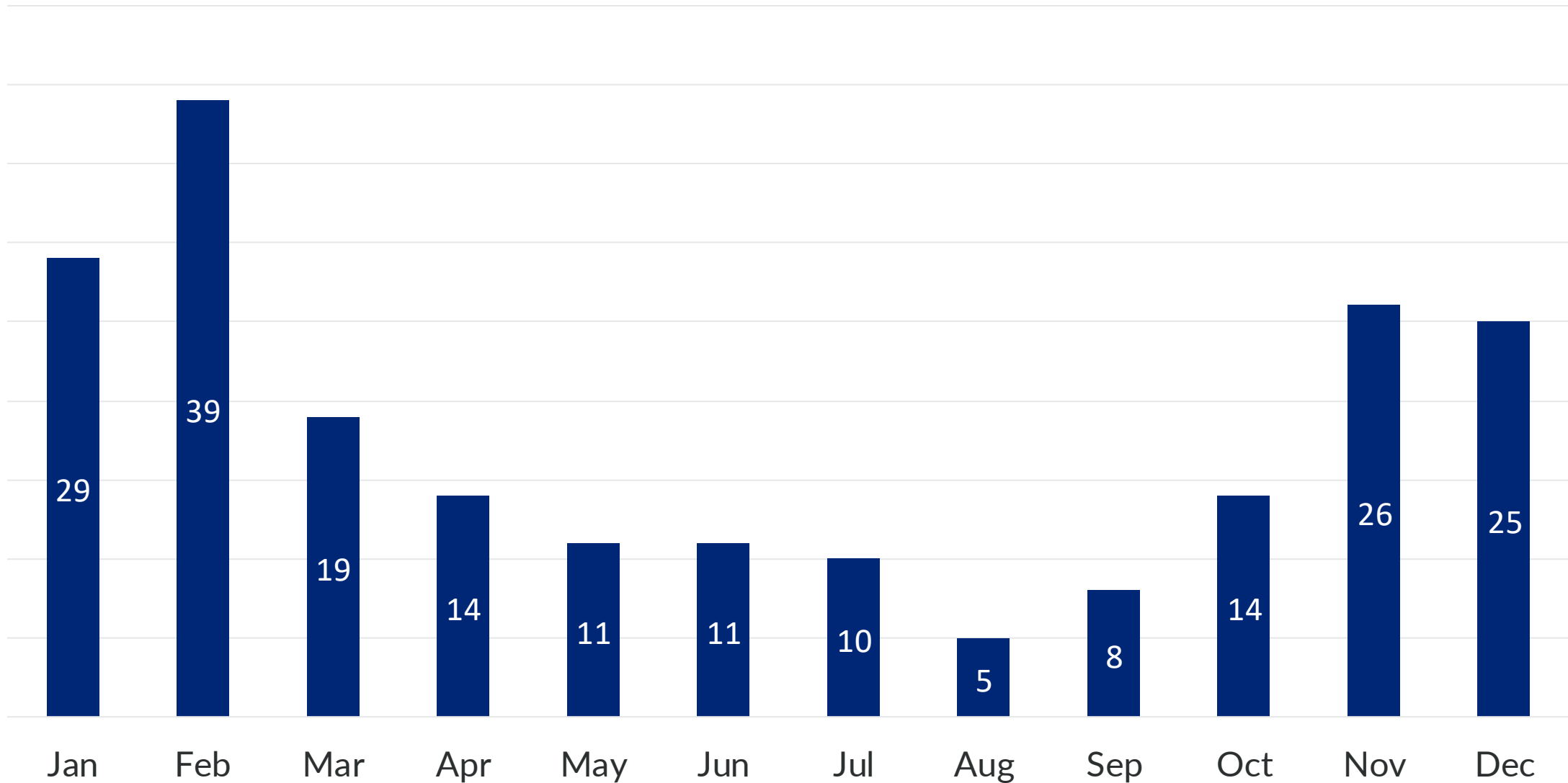


# EMS and ED Provider Calls to the HERO Kids Hotline in 2025

Total: 354



# Oregon Registries for EMS (OREMS) App HERO Kids Searches in 2025 Total Searches: 211



# Final Thoughts and Lessons Learned

- **Build relationships:** F2F and EMSC programs both operate under HRSA performance measures
- **Family-centered:** Include families and youth with diverse experiences early and often, and compensate for time
- **Stakeholders:** Forming workgroups and an advisory committee early is critical
- **Barriers:** Children and youth in foster care may not be able to participate
- **Leverage:** Use existing infrastructure, funding, and relationships
- **Education:** Continuous and foundational to success



# Thank you!



More info: [www.herokidsregistry.org](http://www.herokidsregistry.org)

Contact: [herokids@ohsu.edu](mailto:herokids@ohsu.edu)

