

HERO Kids Registry

An Innovative Program Filling the EMS
and ED Information Gap



2023 ALL-GRANTEE MEETING

CULTIVATING COMMUNITY GROWING COLLABORATION

Speaker Disclosure

We have no financial interests or relationships to disclose.



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Learning objectives

By the end of this session, you should understand the following:

- The purpose and use of the HERO Kids Registry
- Development process of the HERO Kids Registry
- Achievements and milestones
- Lessons learned



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Presenters



Tamara Bakewell, MA
Family Involvement Manager, HRSA Emerging Issues Grant

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 Manager, she serves as the Director of the Family-to-Family Health Information Center and provides technical assistance to Title V related to family experiences and leadership.



Rachel Ford, MPH
Oregon EMSC Program Manager

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 12 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
HERO Kids Registry Program Manager

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 and its education and technology subcommittees.



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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



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



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What is HERO Kids Registry?

- Voluntary, no-cost, secure registry
- Oregon families and young adults share critical health information before an emergency occurs
- Emergency medical services (EMS) and hospital emergency department (ED) providers can quickly and easily access information



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Who is HERO Kids for?



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



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Why register with HERO Kids?

By registering with HERO Kids, families give EMS and ED providers a head start on understanding their child or young adult's medical history and unique needs. The information may help them provide more informed care or comfort.

For example:

- *Flashing lights may trigger seizures*
- *Specific words may calm the child or young adult*
- *Child or young adult does not communicate with spoken language*

This is a way for families to get their words into the ears of EMS



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How does the Registry work?

Logout

Oregon Registries for EMS

POLST HERO Kids

* Last Name

Test

First Name

Kiddo

MI

Registry ID

Date of Birth (MM-DD-YYYY) Clear

07 - 17 - 2019

Approx Age (Years)

AA orems.org

In an emergency: The person calling 911 will give the dispatcher or arriving EMS the HERO Kids Registry ID number, or tell them that the child or young adult is registered (if known)

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

- Call the confidential provider line
- Connect through the OREMS app
- Receive an Emergency Department Information Exchange (EDIE) alert
 - The alert will direct them to the provider line or to view directly within the Collective Medical Portal

The information is available in fewer than 90 seconds.



Who can access 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 Registry information:



- 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



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How families register with HERO Kids

- Register online with a computer or tablet at www.herokidsregistry.org. We recommend having the Registration Guide available.
- Registration takes 15-60 minutes
- Provider-signed emergency information form or protocol letter may be included
- Welcome letter, stickers, and a backpack tag with the HERO Kids Registry ID number will be mailed



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What information will families enter into the Registry?

- Allergies and medications
- Emergency protocol letters
- Emergency Information Forms
- Factors that may impact care
- Medical and/or behavioral conditions
- Medical equipment or technology
- 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

Clear

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



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HERO Kids registration form

- Once registration is 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, schools, etc.



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

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"/>

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Program summary



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



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How Oregon Developed HERO Kids Registry

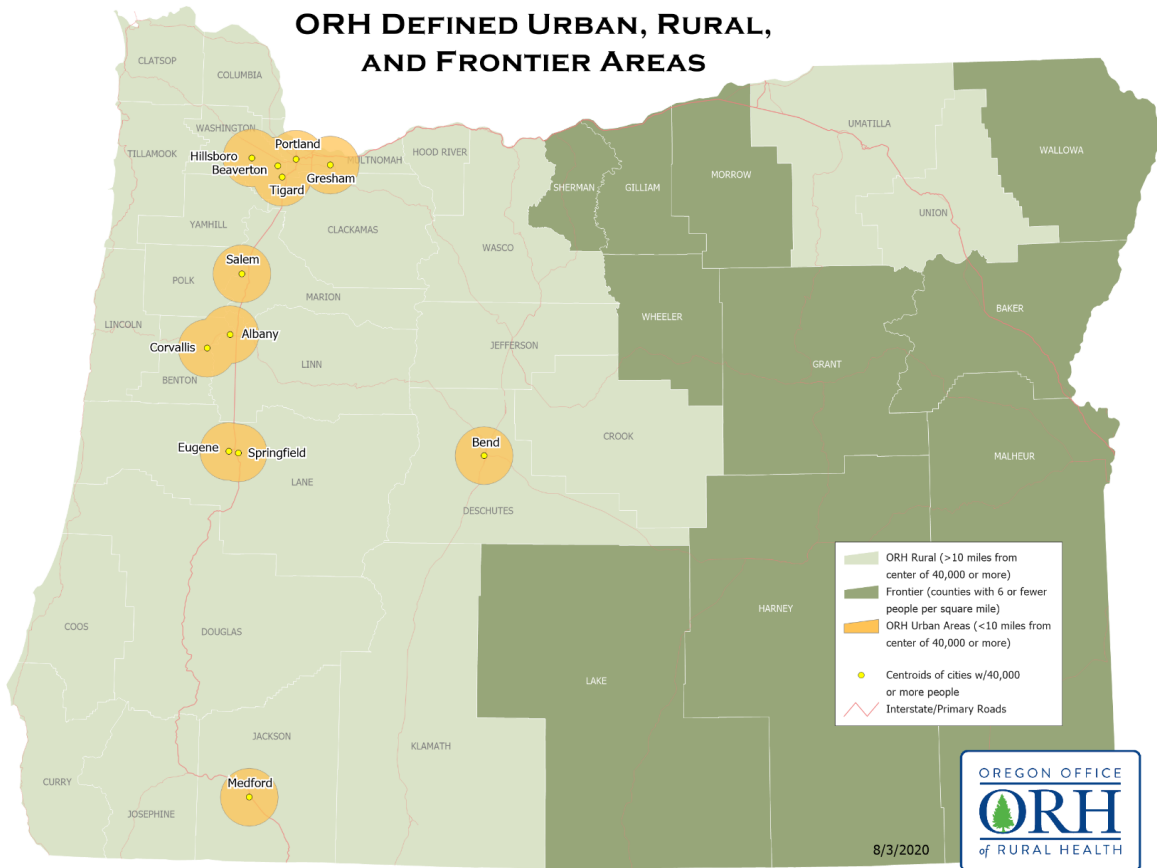


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Overview of Oregon

ORH DEFINED URBAN, RURAL, AND FRONTIER AREAS



Demographics:

- 16% live in rural and frontier areas

Target Population:

- All of Oregon's 869,000 children (174,000 Children and Youth with Special Health Care Needs)

In 2021:

- 16,247 children 0-18 experienced a medical emergency requiring a call to Oregon EMS (OHA '22)



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Enablers

- **Technology:** 13 years success with Oregon Portable Orders for Life Sustaining Treatment (POLST) Registry
- **Workforce:** EMS is trained and familiar with Oregon POLST Registry (OPR)
- **Partnerships:** strong relationships between EMSC, F2F, and Title V
- **Support:** 20+ letters of support from professional organizations, EMS providers, hospitals, and families
- **Funding:** 3 sources



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Oregon POLST Registry

- Began statewide operations December 2009
- Dedicated FTE
- 250,000+ active registrants (OPR '22)
- 2022: hotline received average of 201 calls per month from EMS & EDs (OPR '22)

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

- Sample - Oregon POLST® For Patient Education

Portable Orders for Life-Sustaining Treatment

Follow these medical orders until orders change. Any section not completed implies full treatment for that section.

Patient's Last Name: _____ Patient's First Name: _____ Patient's Middle Name: _____
Patient's Last Name: _____ Patient's First Name: _____ Patient's Middle Name: _____
Date of Birth: (mm/dd/yyyy) _____ Date of Birth: _____ Gender: M F X (optional)
Address (street / city / state / zip): _____

A **Attempt Resuscitation/CPR** **Do Not Attempt Resuscitation/DNR**
Must check Full Treatment in Section B. If patient not in cardiopulmonary arrest, follow orders in B.

B **Comfort Measures Only**. Provide treatments to relieve pain and suffering through the use of any medication by any route, positioning, wound care and other measures. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. Patient prefers no transfer to hospital for life-sustaining treatments. Transfer if comfort needs cannot be met in current location.
Full Treatment. In addition to care described in Comfort Measures Only and Selective Treatment.

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

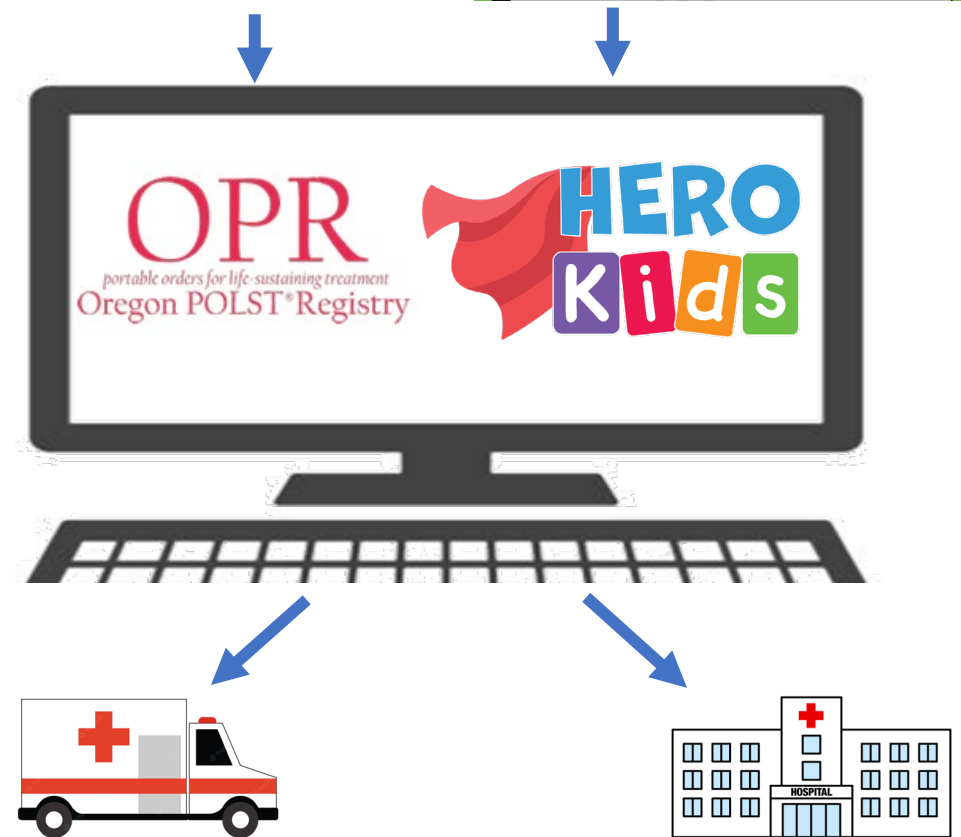
HERO Kids Health Emergency Ready Oregon (HERO) Kids Registry
IN AN EMERGENCY, EVERY MOMENT COUNTS

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 EMSID: 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: _____



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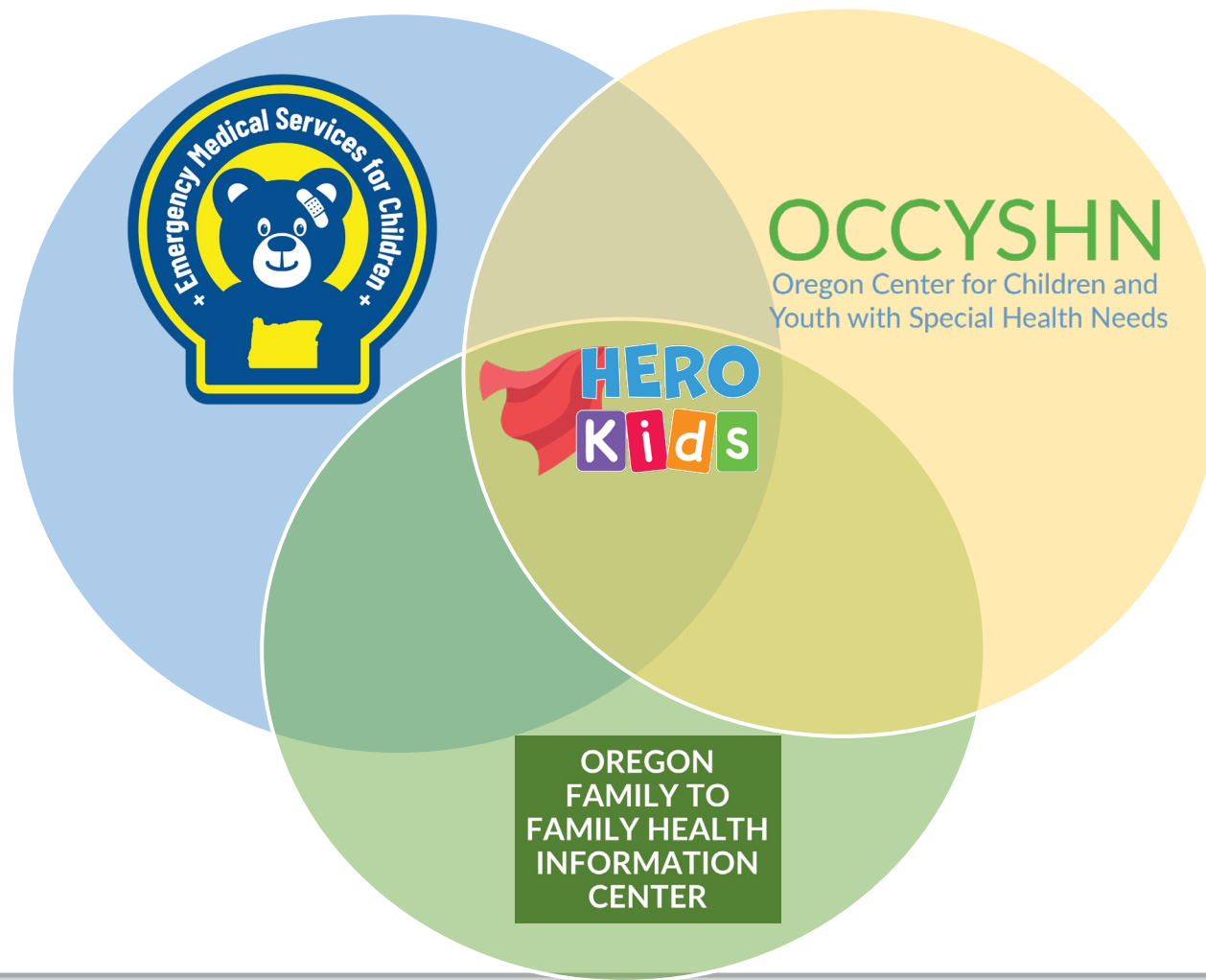
Barriers

- **Technology:** Internet and technology access for first responders and families
- **Workforce:** Outside of population centers, emergency medical services are often volunteer-based
- **Education:** Requires outreach to all families, individuals through age 26, and the health care workforce



Partnership: EMSC, F2F and Title V

- Authentic partnership
- Inclusion at every step
- Continued commitment



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Our diverse team:

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



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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



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Development process: ideas to action

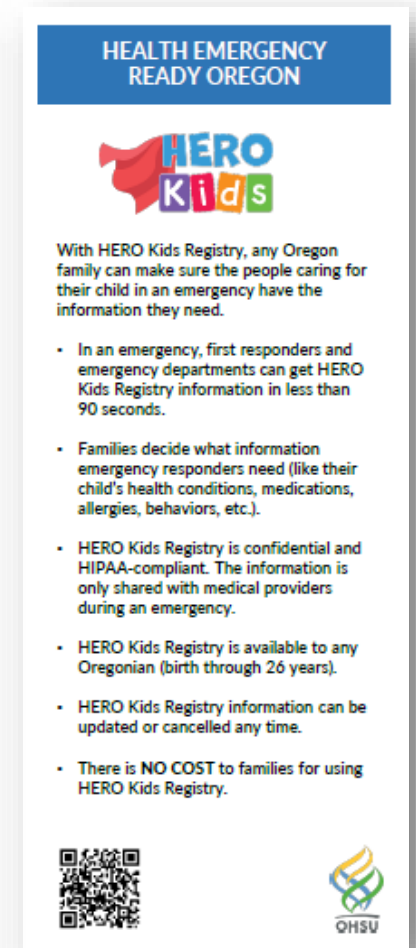
- Business plan
- Letters of support
- Secured start up funds
- Contracted for registry build
- Convened advisory committee and workgroups
- Oregon POLST Registry signed MOU for business office operations



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Development process: implementation

- **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:** Registry hotline available for EMS and ED Providers
- **October 21, 2022:** Launched OREMS app



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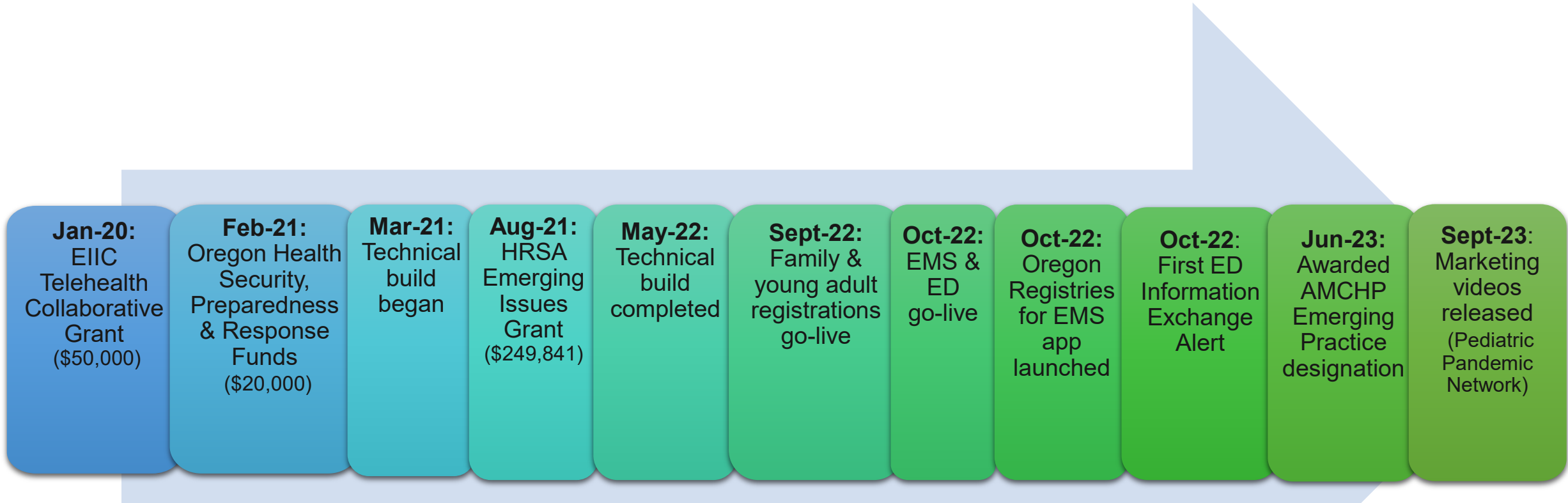
Achievements, Milestones & Lessons Learned



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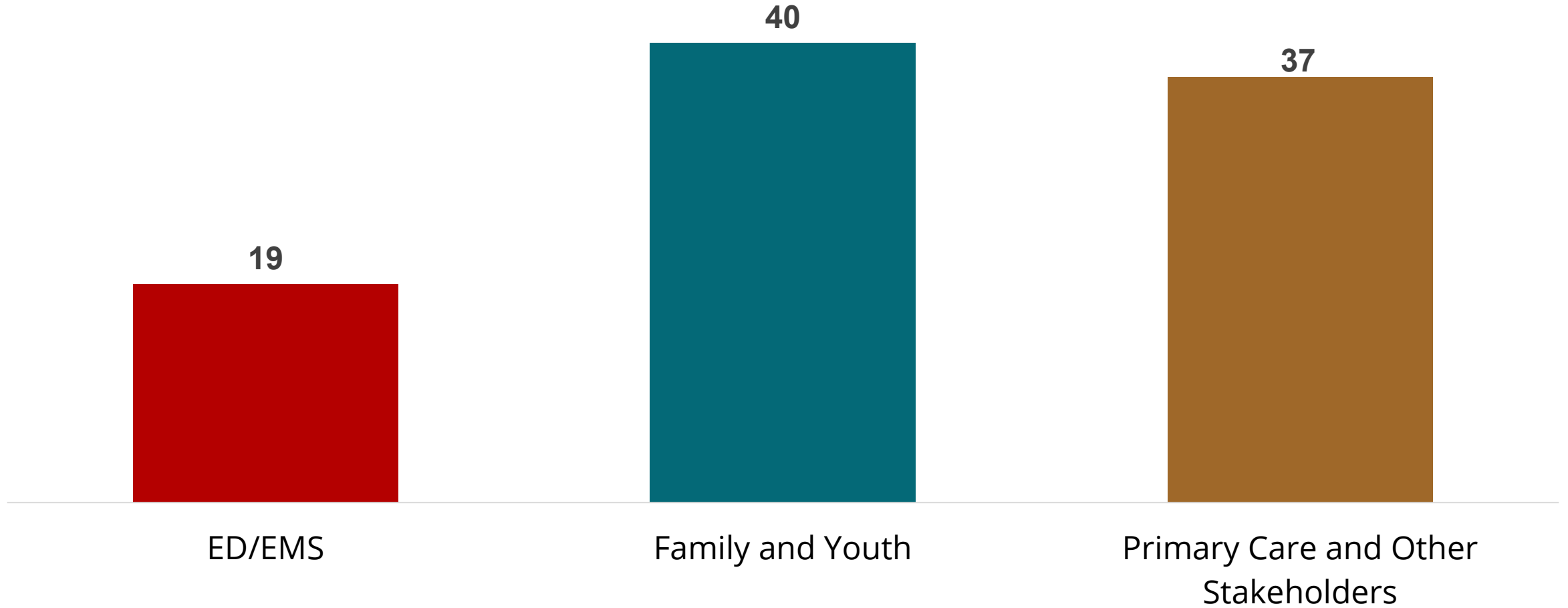
Achievements and Milestones



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Educational Presentations and Conferences

8/1/22-8/31/23



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Social Media

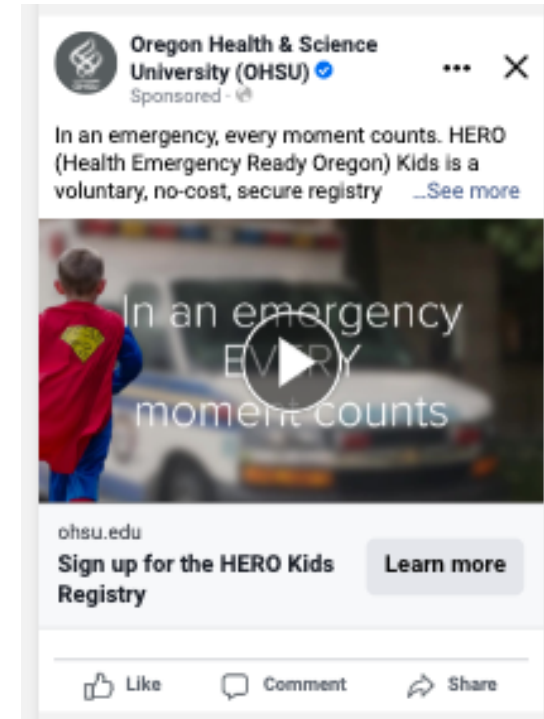
Timeframe: Oct 2022-Jul 2023

Platforms used: Facebook and Instagram

Strategies:

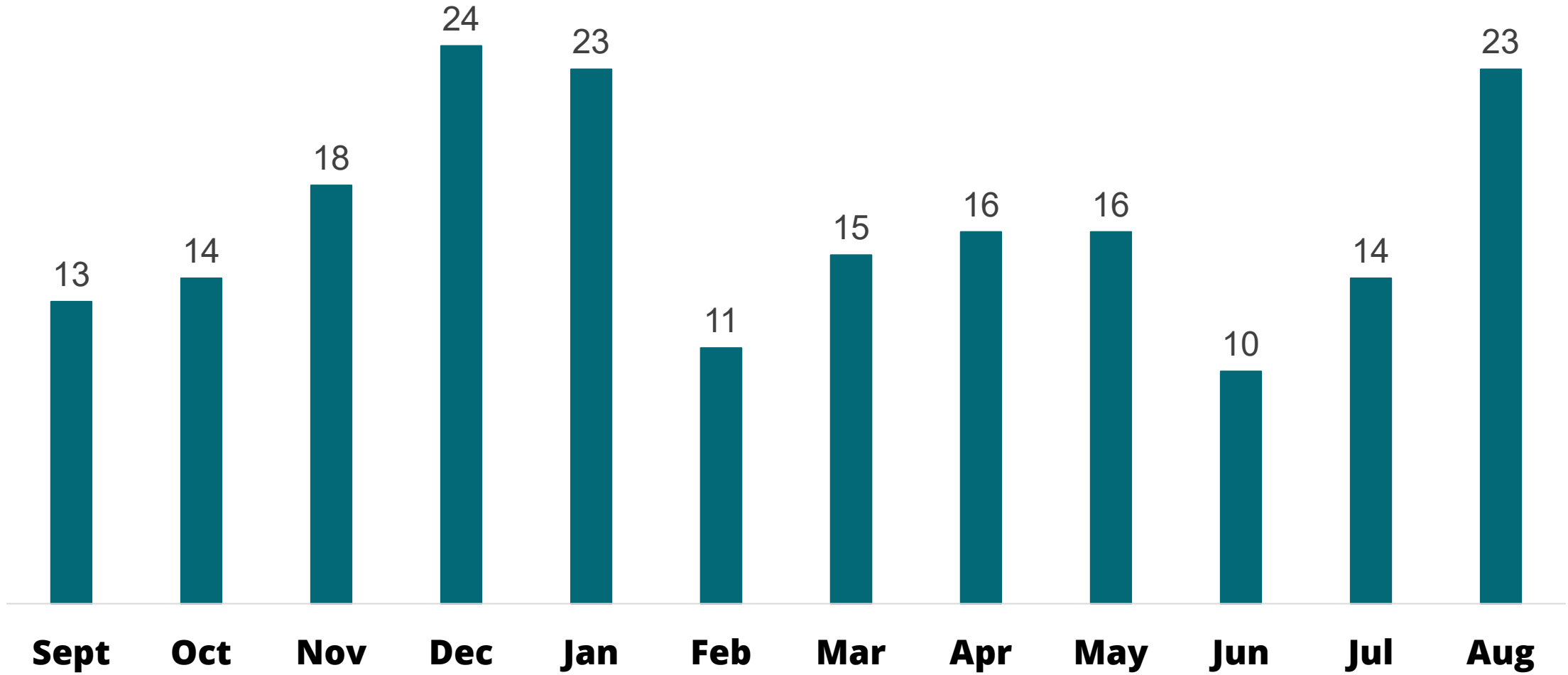
- **Geographic:** People who live in Oregon
- **Genders:** All
- **Age:** 18-65+
- **Interest-based 1:** Families
- **Interest-based 2:** Professionals

Impressions (views): 681,680



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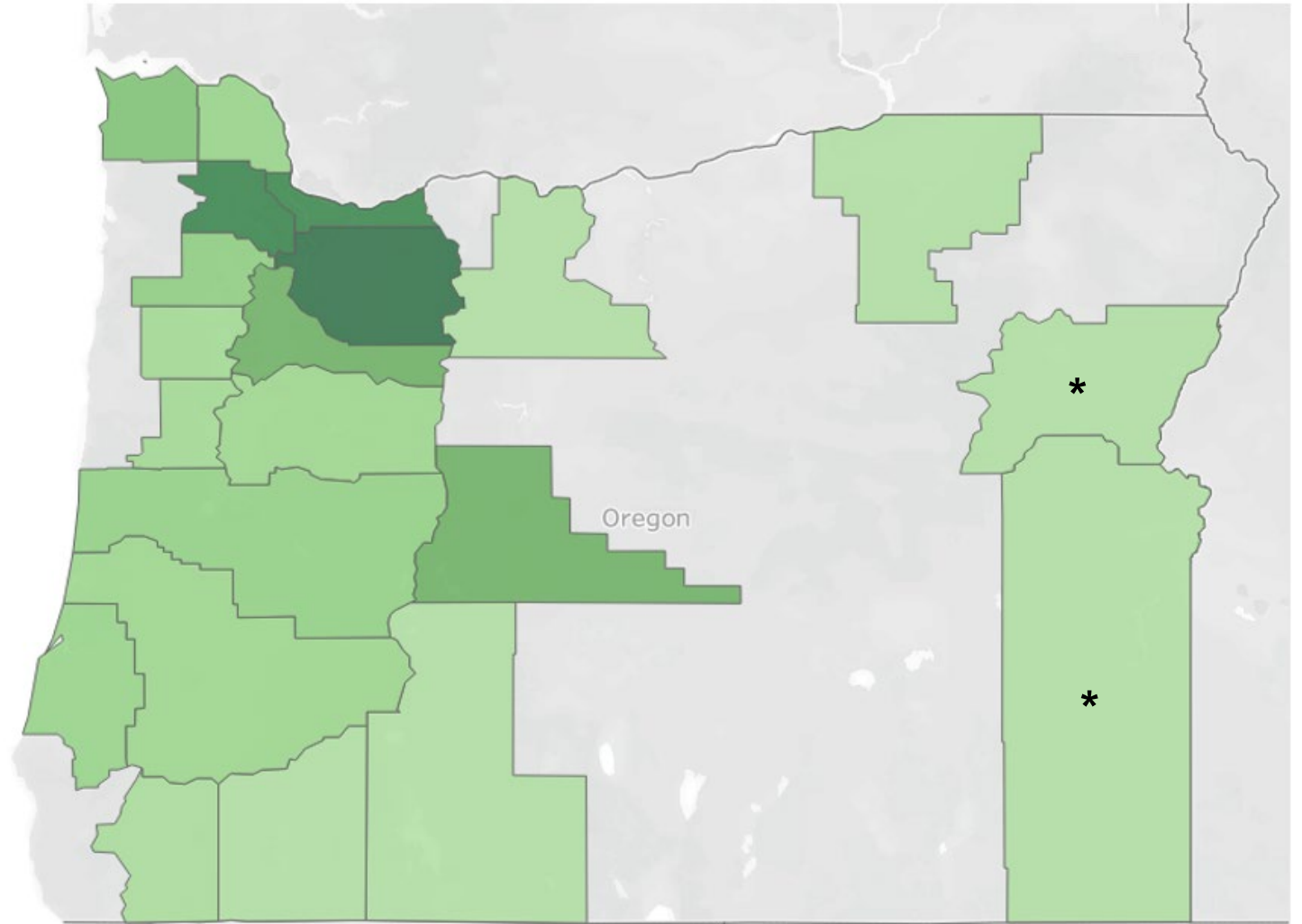
New Registrants, 9/12/22-8/31/23



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Children and Young Adults Registered

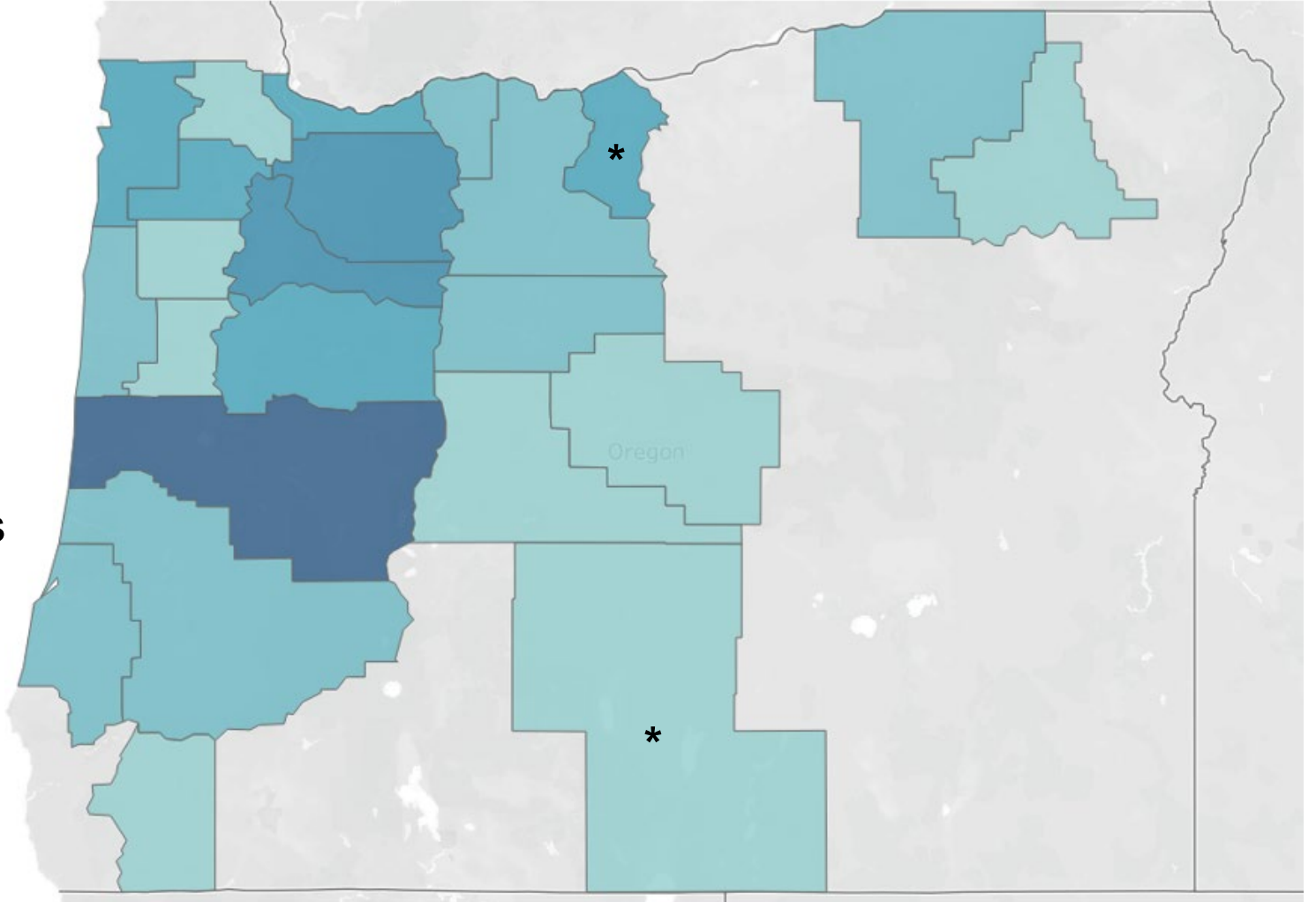
- Registrants in 21 of 36 counties
 - 2 of 21 are Frontier*
 - 19 of 21 are Rural
 - Includes all Urban Centers



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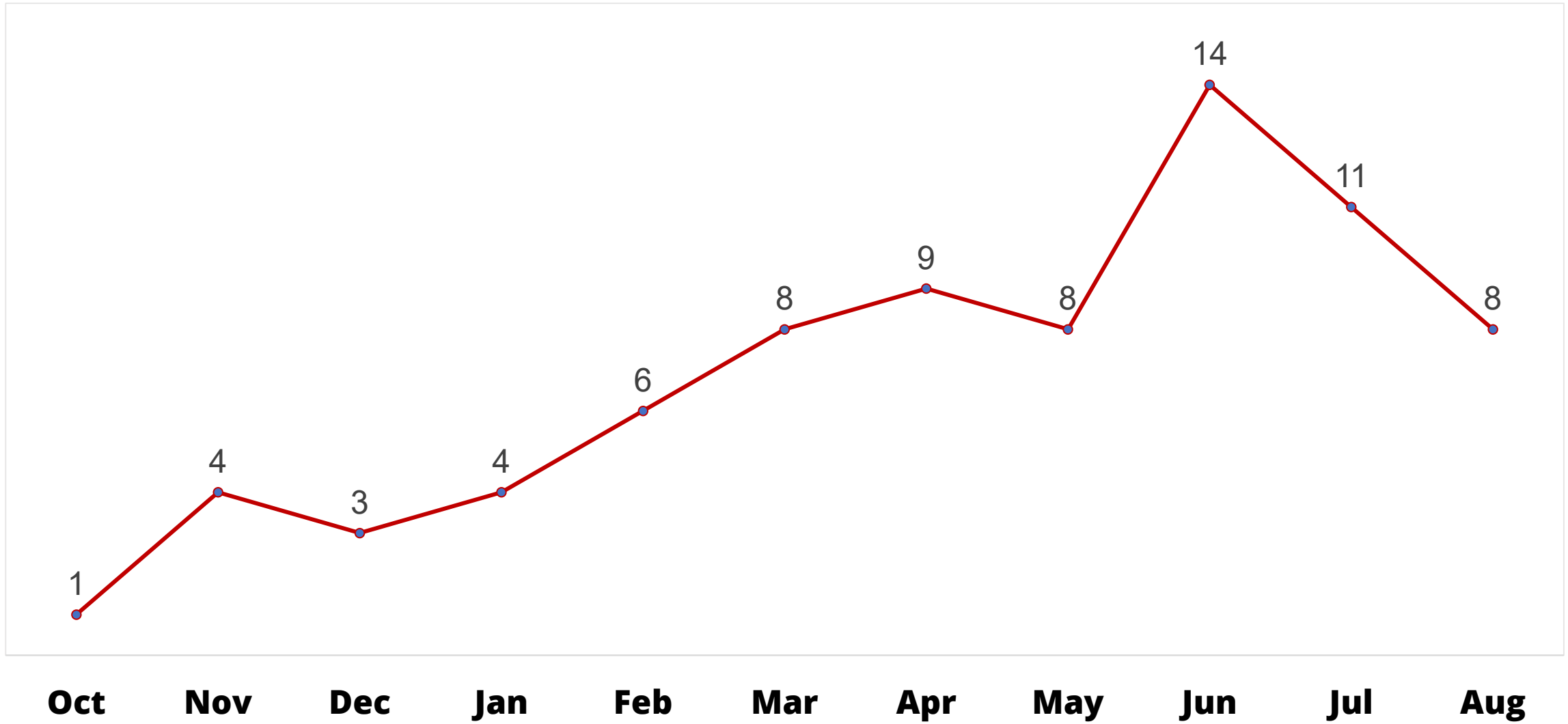
OREMS App: Agency Accounts

- OREMS App is in use in 23 of 36 counties
 - 2 of 23 are Frontier*
 - 21 of 23 are Rural
 - Includes all Urban Centers



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Emergency Department Information Exchange (EDIE) Alerts, 10/01/22-8/31/23



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Looking ahead

Ongoing:

- Marketing and education
 - Continue to work with the Pediatric Pandemic Network (PPN) to improve outreach
 - Quarterly stakeholder updates
- Advisement and feedback from family and youth representatives
- Work with community-based organizations

2024: Looking to legislate program funding



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Lessons Learned

- Build relationship between F2F and EMSC programs
- Include (and compensate) families and young adults with diverse experiences and give them ample time to contribute
- Include stakeholders early in the process
- Leverage existing infrastructure
- Working with child welfare systems requires extra time
- Education is ongoing and foundational to successful implementation



Questions? Contact us!

www.herokidsregistry.org

herokids@ohsu.edu



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