# Advocating for a Brighter Future

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PHA Pulmonary Hypertension Association
Empowered by hope

# Why advocate?

"To raise awareness about racial inequalities in access to PH treatments."

**Because it's fun!**

"To make a difference and fight for the resources patients need, including my daughter."

"To give back to my community and those who advocated before me."

# PHA's advocacy priorities

1. Improving access to clinician-prescribed PH treatments
2. Funding PH research

Current priority bills:

- *Supplemental Oxygen Access Reform Act* (S. 1406, H.R. 2902)
- *Safe Step Act* (S. 2903, H.R. 5509)
- *CONNECT for Health Act (S. 1261, H.R. 4206)*
- *Clinical Trial Modernization Act* (H.R. 3521)
- *Help Ensure Lower Patient Copays Act* (S. 864)

# PHA's advocacy priorities

Advocate for affordable, accessible health insurance coverage

- Extending tax credits to keep ACA Marketplace plans affordable
- Pushing back on Medicaid work requirements

**Calling for community stories:**

Lost health coverage because ACA Marketplace plans cost too much?

At risk of losing Medicaid because of new work requirements next year?

**Share your story to help PHA advocate for better health insurance policies!**

# Your story is POWERFUL!

- Legislators need to hear from their constituents
- You are the expert of your own experience
- Show the real-life impacts of health policies

# PH community accomplishments

- Advancing the SOAR Act & Safe Step Act
- Updated airlines' policy on flying with portable oxygen concentrators
- State legislation banned copay accumulators in CT
- Passed the No Surprises Act

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Home / Article / Survey exposes dead end for patients needing high-flow oxygen

## SURVEY EXPOSES DEAD END FOR PATIENTS NEEDING HIGH-FLOW OXYGEN

Providers

Tracy Orzel
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WASHINGTON – Some patients are staying in acute-care beds longer than medically necessary because hospitals cannot find home medical equipment (HME) providers willing or able to furnish liquid oxygen services at home, says Katie Kroner, vice president of advocacy and patient engagement for the Pulmonary Hypertension Association (PHA).

"As a physician, you can write a prescription for liquid oxygen as many times as you want," she said. "It's not going to get filled because the suppliers literally have divested themselves of that equipment."

A national survey conducted by PHA and other respiratory organizations found 94% of 54 clinicians representing 40 medical centers reported at least one oxygen-related discharge delay per month. One-third reported six or more, and most delays extended a hospital stay by at least two days.

**A market that has disappeared**

Behind those delays is a reimbursement model that has driven suppliers out of the liquid oxygen market, says Kroner.

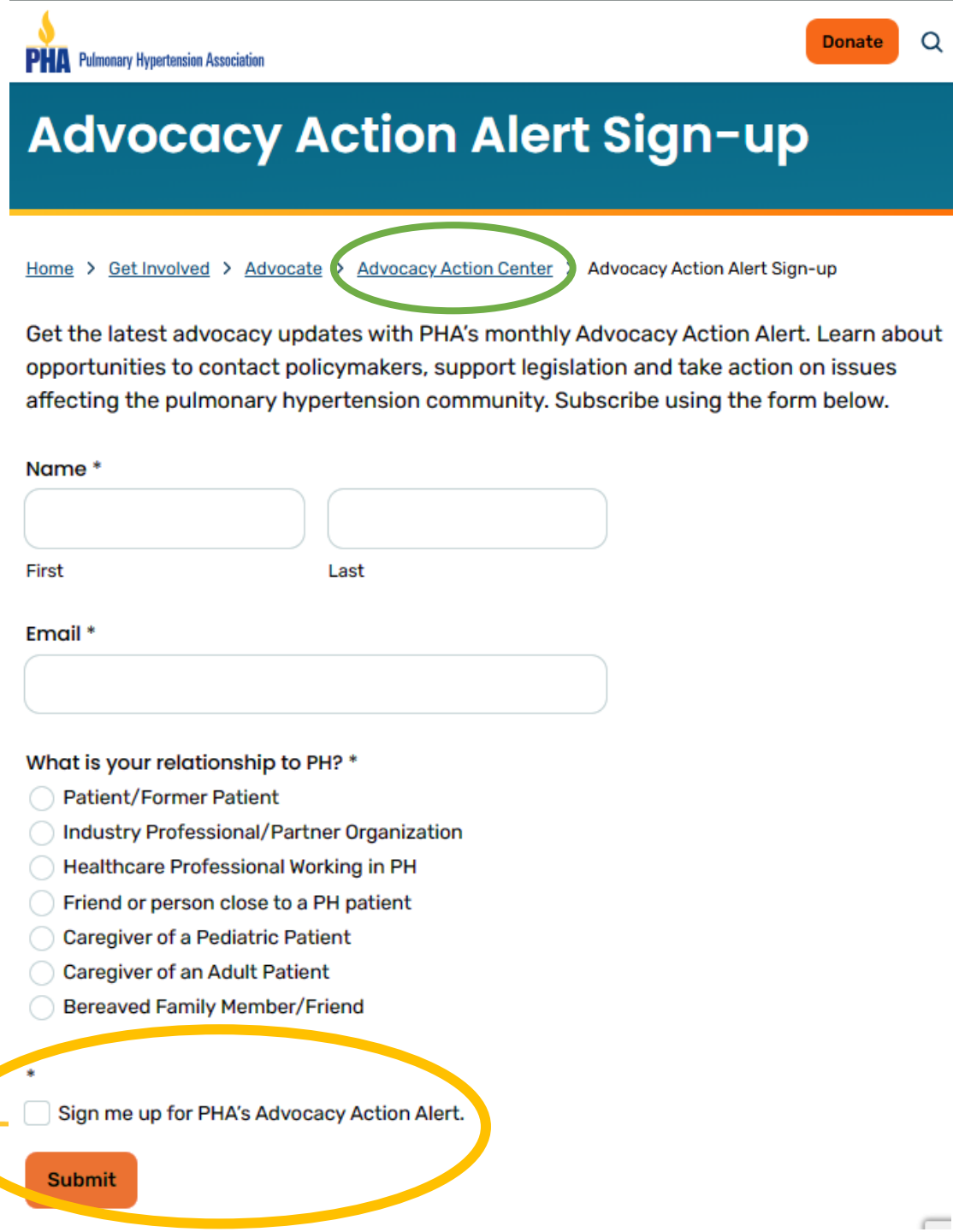
# Ways to advocate

- Sending emails & making calls
- Posting about bills online
- Writing a Letter to the Editor
- Meetings with offices
  - Virtual or in-person
  - District visits & D.C. Hill Days

# Read PHA's advocacy newsletter

- Be the first to learn of new advocacy opportunities.
- Stay in the loop with monthly legislative updates.

Sign up at [PHAssociation.org/alert-sign-up](PHAssociation.org/alert-sign-up)

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