



# Media Toolkit

## How to amplify your story in the local media



### Why tell your story?

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Telling your PKU story can be incredibly powerful for several reasons: raising awareness, empowering others, encouraging research and funding, shaping policy and creating a support network. It can also be a tool for self-expression and healing. Each story shared can have a ripple effect inspiring change far beyond the individual experience.

### How do I contact the media?

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Reaching out is easier than you think—reporters are always looking for great stories!

Start local by searching “[YOUR AREA] local media,” then expand to national outlets. Consider pitching to non-traditional media sources like podcasts, blogs, or vlogs.

For your story, reach out to relevant reporters, organizations, or institutions. Use general inquiry emails (e.g., tips@, info@), online forms, main phone lines, or social media.

### What do I say?

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Be a valuable resource for the reporter! Share some basic facts about Phenylketonuria. Frame your story to be newsworthy with a catchy subject line, a concise pitch, and a timely, relevant hook.

#### **Possible Story Angles:**

**Public Policy:** Local & National legislation related to medical nutrition/ newborn screening.

**Event-Based Stories:** Local or national events and fundraisers, PKU Awareness Day, Rare Disease Day, PKU Awareness Month, etc.

**Treatment Impact:** How diet or new therapies have made a difference for you.

**Living with PKU:** Personal growth, achievements, and the impact of Newborn Screening.



## How do I prepare once I have secured media coverage?

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Congratulations! The media is interested in sharing your story. Time to brush up on your PKU facts and grab some props! Get to know your reporter, research them and find common ground to connect to break the ice.

### What to Expect:

- The reporter may ask what you're comfortable sharing—it's up to you!
- Be confident and intentional with your message; you are the PKU expert, and your words may be used as shared.
- Expect not to review the final piece before publication or broadcast.
- Offer additional expert sources. Suggest a clinician, another PKU family, or a local/regional PKU group leader. If applicable, mention that the NPKUA can serve as a secondary source.

### Prop Ideas:

- Medical Food & Formula: Bring examples and compare prices to store-bought equivalents.
- Documents: Examples of insurance denials or related informational factsheet.
- Other: Still photos, visual representation of diet details (how much protein is in...)

### Call To Action:

Decide on a call to action to direct readers to further resources, ex: NPKUA's website. "To learn more about PKU go to [www.npkua.org](http://www.npkua.org)." "To help us find a cure go to [www.npkua.org](http://www.npkua.org)."

## What are my next steps after media coverage?

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Thank the reporter, share the story on social media (tag them and use community hashtags, e.g. #pku, #npkua, #medicalnutrition), and notify NPKUA for amplification. If relevant, follow up in 6–12 months for updates (e.g., ongoing legislation).

#### Examples of PKU Stories in local News:

Television:  
[KTAL & KMSS](#)  
[NBC Philadelphia](#)

Digital News Source:  
[ABC7 News](#)

Newspaper:  
[Boston Herald](#)

#### Examples of PKU stories in national news:

Television:  
[CBS News](#)

Digital Outlets:  
[The Today Show](#)  
[People Magazine](#)  
[Washington Post](#)

National institution:  
[Costco Connection](#)

#### Examples of organizations that have featured PKU:

Podcast:  
[Patients Rising](#)

Rare Disease Orgs:  
[Global Genes](#)  
[Check Rare](#)  
[NORD](#)