PKU Proclamation Toolkit

A Guide to Securing a PKU Awareness Proclamation in Your Town, City, or County

What Is a Proclamation?

A proclamation is an official statement issued by a mayor, city council, county executive, governor, or other elected official that recognizes an important cause, event, or awareness month.

PKU proclamations help:

- Raise awareness about Phenylketonuria (PKU)
- Educate the public about newborn screening and rare diseases
- Recognize the experiences of individuals and families living with PKU
- Encourage community support and advocacy
- Highlight the importance of access to treatment and medical nutrition

Even small local proclamations can make a big impact.

Step 1: Decide What You Are Requesting

You can request a proclamation for:

- PKU Awareness Month (May)
- National PKU Awareness Day

Possible issuing offices:

- Mayor
- City Council
- County Commissioners Court
- Governor
- State Legislature

Tip: Start local - city and county proclamations are often easier and faster to obtain.

Step 2: Research Local Requirements

Check city and state websites to determine the specific requirements for requesting a proclamation. Find out how much notice is required for the request, and whether there are specific language or application requirements. Google can be helpful!

Step 3: Find the Right Contact

Search online for:

- "City of [Your City] proclamation request"
- "Mayor's office proclamation request"
- "County proclamation application"

You may find:

- An online request form
- An email address
- A downloadable application

Helpful information to gather:

- Submission deadlines
- Required lead time (often 2–8 weeks)
- Whether they provide their own proclamation template

Step 4: Prepare and Submit Your Request

Most offices will ask for:

- Your name and contact information
- The requested proclamation date
- A short explanation of the cause
- Draft proclamation language

Keep your request concise, respectful, and personal.

Sample Request Email:

Subject: Request for PKU Awareness Proclamation

Dear [Mayor/Commissioner/Council Member Name],

My name is [Name], and I am a resident of [City/County]. I am reaching out to respectfully request a proclamation recognizing [December 3rd PKU Awareness Day/May PKU Awareness Month] in [City/County].

Phenylketonuria (PKU) is a rare inherited metabolic disorder identified through newborn screening. Individuals with PKU must carefully manage their diets and treatment throughout their lives to prevent serious health complications. To learn more about the condition, please visit https://www.npkua.org/about-pku/.

A proclamation would help raise awareness in our community about PKU, rare diseases, and the importance of newborn screening and access to treatment.

I have attached draft proclamation language for your consideration. Thank you for your time and support of the rare disease community.

Sincerely,
[Your Name]
[Phone Number]
[Email Address]

Sample Proclamation Language:

PROCLAMATION

PKU Awareness Day/Month

WHEREAS, Phenylketonuria (PKU) is a rare inherited metabolic disorder in which the body cannot properly process phenylalanine, an amino acid found in protein-containing foods; and

WHEREAS, PKU is identified through newborn screening shortly after birth, allowing early treatment and management that can prevent serious health complications; and

WHEREAS, individuals living with PKU must adhere to a lifelong, medically necessary treatment plan that may include a specialized low-protein diet, medical formula, and ongoing monitoring; and

WHEREAS, families and individuals affected by PKU demonstrate extraordinary resilience, advocacy, and commitment in navigating the daily challenges of managing a rare disease; and

WHEREAS, increasing awareness and understanding of PKU can help improve support, access to care, and quality of life for those impacted by this condition;

NOW, THEREFORE, I, [Official Name], [Title] of [City/County/State], do hereby proclaim [DAY/MONTH] as:

"PKU Awareness Day/Month"

and encourage all residents to learn more about PKU and support individuals and families living with rare diseases.

Step 5: Follow Up

If you do not hear back within 1–2 weeks:

- Send a polite follow-up email
- Call the office if appropriate
- Offer to answer questions or provide additional information

Persistence is often part of the process.

Step 6: Celebrate and Share

Once approved:

- Notify us so we can celebrate your success! Email sarah@npkua.org to share the news.
- Attend the proclamation presentation if invited
- Take photos
- Share on social media
- Tag local officials and organizations
- Send photos and copies to NPKUA

Ideas for sharing:

- Post a family photo
- Share your PKU story
- Educate others about newborn screening
- Thank local leaders publicly

Tips for Success:

- Start early whenever possible
- Keep communications professional and brief
- Personal stories can strengthen your request
- Don't be discouraged if one office declines
- Smaller communities are often very receptive

Optional Additions

You may also include:

- Local patient or family stories
- Information about local or national PKU Awareness Day or Month events

Need Help?

If you need assistance drafting language or navigating the process, reach out to National PKU Alliance for support and resources.

Together, we can help increase awareness and understanding of PKU in communities across the country!