



JUNE 24

Cystinuria Awareness Day

Thank you for helping to spread the word about **Cystinuria Awareness Day**, which takes place on **Monday, June 24, 2024!**

Together, we can raise awareness of cystinuria through a coordinated **SOCIAL MEDIA CAMPAIGN** during the week of **June 24 - 28**.

5 EASY WAYS TO PARTICIPATE:

1 **Frequently share social media content and graphics during the week of June 24 and [your state legislators](#) every time you post.** To make it easy, you can simply copy and paste or download from the content samples provided below. If you or someone in your life has been personally impacted by cystinuria, please consider **customizing these samples and/or creating your own social media content.** It's important for policymakers, healthcare providers, the media, and the public to hear about the personal experiences of people living with cystinuria. Tag [your state legislators](#) and legislatures in your posts, finding their social media handles on their respective websites. To tag, simply type @ and then the respective username - that account will then be able to view your post.

Some Creative Ways to Customize Your Content to Engage Your Social Media Audience:

- Share a short video or a personal photo that shares and shows something about YOUR cystinuria experience
 - Example: *show a container that holds the amount of water you drink in a day and tell why.* "I drink this much water every day. Why? Because it helps to manage a rare, genetic kidney disorder I have called cystinuria. I'm sharing this with you because today is cystinuria Awareness Day. You can learn more at [cystinuria.org](#)".
 - Example: *share a video or photo showing your kidney stones.* "I'm a real-life rock star, and I have the stones to prove it! I have a rare kidney condition called cystinuria that causes the formation of frequent and recurrent kidney stones like these. Cystinuria Awareness Day is this week, and I hope you'll visit [cystinuria.org](#) to learn more!

- 2 **Change your Facebook and LinkedIn cover photos to the design provided with instructions below.**
- 3 **Use a cystinuria awareness virtual meeting (Zoom) background.** The background design options and instructions on how to use are provided below.
- 4 **Share this social media toolkit document with your family, caregivers, friends, coworkers, healthcare providers, and others** – and ask them to also participate through these five easy ways!
- 5 **Share your story and/or the reasons why you care about cystinuria Awareness Day with your lawmakers.** You can find contact information for your federal and state lawmakers by simply entering your zip code [here](#).

HOW TO SHARE ON SOCIAL MEDIA

Please share the awareness day information on ALL your organizational and individual social media accounts, including Twitter, Facebook, Instagram, and LinkedIn. Please use the hashtags **#CystinuriaDay2024 #rarekidneystones and #rarediseaseawareness** every time you share. You can post the content and graphics separately or combine them however you wish.

Note: because we want to raise awareness of cystinuria among policymakers, we encourage you to tag [your state legislators](#) and legislatures in your posts. You can find their social media handles on their respective websites.

Sample Social Media Content

Can be combined with graphic options below or used alone

Twitter / X:

Cystinuria Awareness Day is June 24! #cystinuria is a rare, serious genetic disorder characterized by frequent and recurrent #kidney stone formation. Learn more at [cystinuria.org](#)! #CystinuriaDay2024 #rarekidneystones #rarediseaseawareness

1 in 10,000 Americans has #cystinuria, a #raredisease causing frequent and recurrent #kidney stone formation. June 24 is Cystinuria Awareness Day. Learn more at [cystinuria.org](#). #CystinuriaDay2024 #rarekidneystones #rarediseaseawareness

Learn more about #cystinuria, a #raredisease that can lead to chronic #kidneydisease if not properly managed. June 24 is Cystinuria Awareness Day! Visit [cystinuria.org](#). #CystinuriaDay2024 #rarekidneystones and #rarediseaseawareness

Facebook / LinkedIn:

June 24 is Cystinuria Awareness Day. Cystinuria is a rare, serious genetic disorder characterized by frequent and recurrent kidney stone formation. It affects both men and women and is a lifelong, chronic condition. While cystinuria has no cure, it can be managed. Early diagnosis is important. Learn more at cystinuria.org.

#CystinuriaDay2024 #rarekidneystones and #rarediseaseawareness

Cystinuria is a rare disease that causes frequent and recurrent kidney stone formation. It affects about 1 in 10,000 people in the US. Cystinuria Awareness Day is observed on June 24 – learn more at cystinuria.org.

#CystinuriaDay2024 #rarekidneystones and #rarediseaseawareness

Cystinuria can lead to chronic kidney disease, which, if not properly managed, can worsen and become kidney failure requiring dialysis or a kidney transplant. Early diagnosis and treatment are important. Cystinuria Awareness Day is June 24 – learn more at cystinuria.org.

#CystinuriaDay2024 #rarekidneystones and #rarediseaseawareness

June 24 is Cystinuria Awareness Day. Treatment for patients with cystinuria often focuses on drinking more fluids and reducing foods that are high in sodium and in animal protein. Medications can also help reduce the formation of cystine stones in the kidneys. Learn more at cystinuria.org.

#CystinuriaDay2024 #rarekidneystones and #rarediseaseawareness

Instagram:

Cystinuria Awareness Day is held on June 24. Cystinuria is a rare, serious genetic disorder characterized by frequent and recurrent kidney stone formation. It affects both men and women and is a lifelong, chronic condition. While cystinuria has no cure, it can be managed. Early diagnosis and ongoing management are important. Learn more at cystinuria.org. #CystinuriaDay2024 #rarekidneystones #rarediseaseawareness #kidneydisease #kidney

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#kidneydisease #kidney

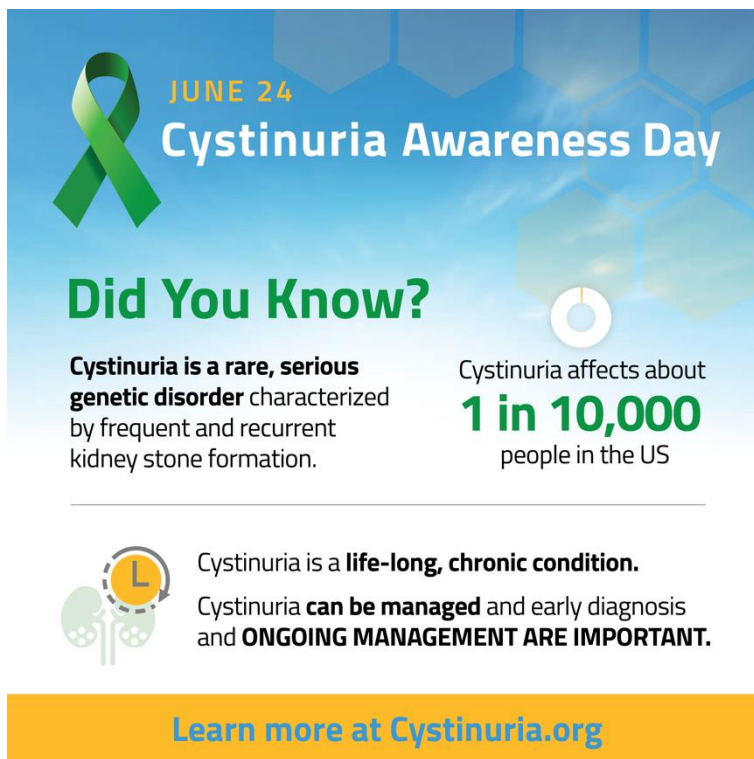
June 24 is Cystinuria Awareness Day. Treatment for patients with cystinuria often focuses on drinking more fluids and reducing foods that are high in sodium and in animal protein. Medications can also help reduce the formation of cystine stones in the kidneys. Learn more at [cystinuria.org](https://www.cystinuria.org). #CystinuriaDay2024 #rarekidneystones #rarediseaseawareness #kidneydisease #kidney

Sample Social Media Graphics

These can be combined with above content options or used alone

Uploading Instructions:

Copy and paste the images below or download the preferred image to an accessible folder on a computer or to the photos app on a phone. Go to the website/app of your choosing, and upload the image with any of the caption options above accompanied by the shareable hashtags: #CystinuriaDay2024 #rarekidneystones and #rarediseaseawareness



The graphic features a blue background with a green awareness ribbon on the left. The text 'JUNE 24 Cystinuria Awareness Day' is prominently displayed. Below this, a 'Did You Know?' section provides key facts: Cystinuria is a rare, serious genetic disorder characterized by frequent and recurrent kidney stone formation, and it affects about 1 in 10,000 people in the US. A bottom section states that Cystinuria is a life-long, chronic condition and can be managed, emphasizing that early diagnosis and ongoing management are important. The graphic concludes with a call to action to learn more at Cystinuria.org.

JUNE 24
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Did You Know?

Cystinuria is a rare, serious genetic disorder characterized by frequent and recurrent kidney stone formation.

Cystinuria affects about
1 in 10,000
people in the US

Cystinuria is a **life-long, chronic condition**.

Cystinuria **can be managed** and early diagnosis and **ONGOING MANAGEMENT ARE IMPORTANT**.

Learn more at [Cystinuria.org](https://www.cystinuria.org)



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Cystinuria Awareness Day

Cystinuria is a rare, serious genetic disorder characterized by frequent and recurrent kidney stone formation.

Cystinuria can be managed and **early diagnosis** and **Ongoing management** are important.

>80% of people with Cystinuria develop their first stones by the age of 20



about **30-40%** of people get their first stones in their teens



Children can also have cystine stones — **8-10%** of kidney stones in children are cystine stones

[Learn more at Cystinuria.org](http://Cystinuria.org)

AWARENESS RIBBONS



JUNE 24

Cystinuria Awareness Day

Sample Social Media Content and Photos

Facebook / Twitter (X) / Instagram / LinkedIn:

I drink 3 liters of water every day to help me manage my Cystinuria, a rare, genetic kidney disorder that causes recurrent kidney stones. Learn more at cystinuria.org.

#CystinuriaDay2024 #rarekidneystones #rarediseaseawareness #kidneydisease #kidney

(You can use photo below or one of your own)



I'm a real-life ROCK STAR with the stones to prove it! Frequent and recurrent kidney stones are signs of #cystinuria, the rare kidney disorder that I live with. Learn more at cystinuria.org.

#rarekidneystones #rarediseaseawareness #kidneydisease #kidney

(You can use photo below or share your own)



Virtual Background Uploading Instructions

To upload either image below as a virtual background, start by downloading the images to an accessible folder on your computer.

Zoom:

Then open the Zoom application and click on the setting button in the top right corner of the screen directly below your initials. Once you are in settings, select the Background & Filters button from the left-hand side of the screen. You should see a few options for a virtual background. For this banner to appear, click on the 'plus' button in the middle of the right-hand side of the screen. From there, you will be able to select either image option to successfully upload the Cystinuria Awareness Day Background image.

Webex:

To set your virtual background before you join a meeting, click Change background on the preview screen and choose the background that you want to use:

- To use a default virtual background, click the one you want.
- To use your own image, animated GIF, or video file for the virtual background, click the + icon.

To change your background during a meeting, click the Video options icon Video

options icon, choose Change virtual background and select the type of background you want. When you're ready for everyone in the meeting to see your background, click Apply. Webex remembers your selection for your next meeting.

Microsoft Teams:

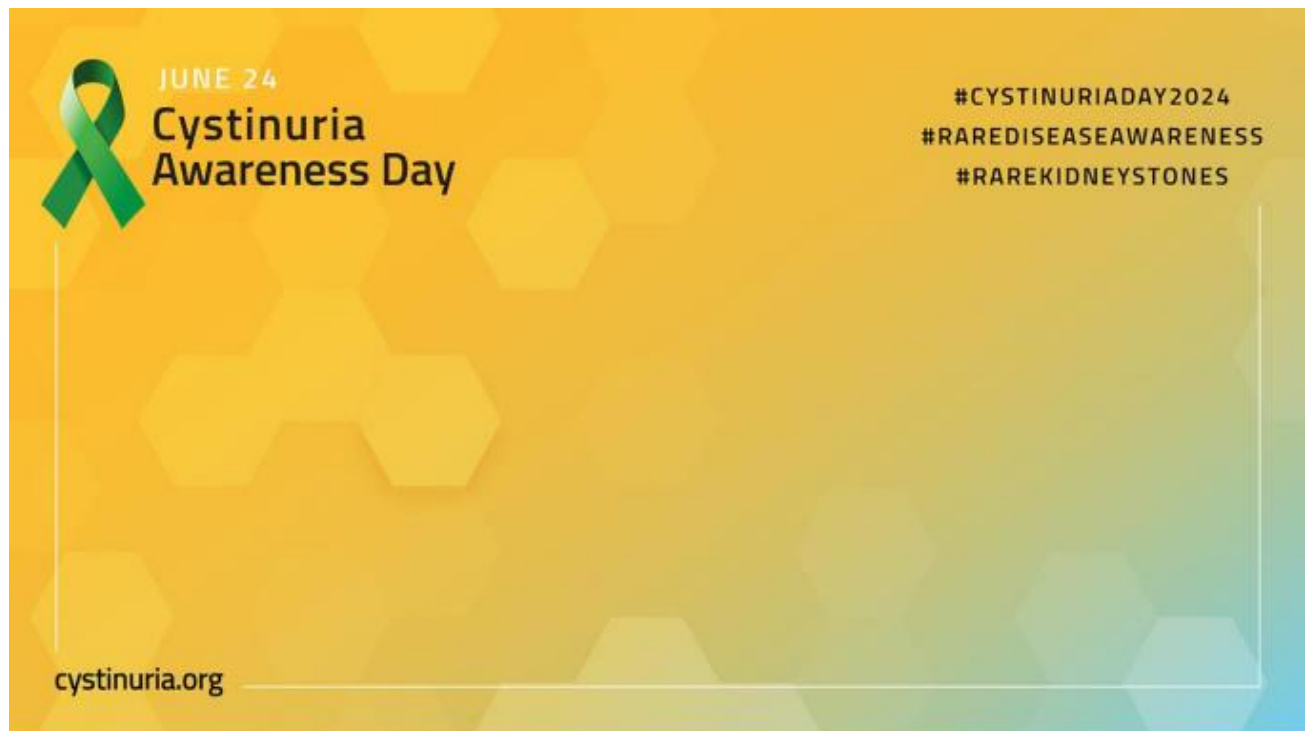
While you're setting up your video and audio before joining a meeting, turn on your camera and select Effects and avatars. Pre-meeting Effects and avatars icon > Video effects. Select a Teams background to apply it to your video feed, or upload and apply your own. To use an image of your own, select More video effects > Add new and then select one to upload from your computer. Make sure it's a .JPG, .PNG, or .BMP file.

To change your background during a meeting, go to your meeting controls, select More actions *** > Effects and avatars 🖥️. To upload an image of your own, select Add new and pick a .JPG, .PNG, or .BMP file from your computer. To turn off background effects, select None. Select Preview to see how your chosen background looks before you apply it, and then select Apply.

Option 1:



Option 2:



Facebook/LinkedIn Cover Banner Image

Uploading Instructions:

To apply this banner image to a Facebook profile, simply download the image below and save it to an accessible folder on your computer or save it as an image on a phone. Go to the Facebook website/app and find your personal profile page. Once you click on your profile, find the camera icon at the bottom left corner of the cover banner. Select the second option, 'upload photo', and find the banner image previously downloaded. Once that image is selected, the banner should be uploaded to your profile representing the Cystinuria Awareness Day image.

