

ALL OF US

Who Support Pennsylvanians Living with Rare Diseases Would Benefit from Better Information About their Specific Needs.

Will you help us to collect this critical data through our statewide survey?



This toolkit makes the task as simple as possible ... we promise!

OUR SURVEY: The Pennsylvania Rare Disease Advisory Council (PARDAC) is currently conducting a survey to provide a better understanding of the needs of our Commonwealth's rare disease community. The survey is confidential, takes less than 10 minutes to complete, and can be taken by any Pennsylvanian living with a rare disease (or a parent/guardian/caregiver if the patient is under 18 or unable to complete the survey on his or her own).

HOW YOU CAN HELP

Partner with us to ensure participation from as many eligible survey takers as possible from across Pennsylvania by sharing the survey through the tools provided below.

Simple ways to share this information:

1. Follow the PARDAC's social media accounts and share what we have already posted to promote the survey.
Follow us:  @PARareDisease  PA Rare Disease Advisory Council  pararediseaseadvisorycouncil
2. Post survey information on your own social media channels. See *sample content and graphics provided in Sections A and C below*.
3. Place survey information on your website. See *sample content and graphics provided in Sections B and C below*.
4. Include information on the survey in your organization's e-newsletter or as a standalone e-mail blast to your networks/constituents. See *sample content and graphics provided in Sections B and C below*.
5. Print the posters we have provided and display them anywhere people living with rare diseases might see them (at support group meetings, community bulletin boards, tabling at health fairs, advocacy days, family days, etc.). Posters have been included as attachments to the e-mail or you can find them at pardac.org/resources/.



SECTION A:

Sample Social Media Content

Please feel free to copy and paste this content or customize it to best represent the specific rare disease community you serve.



FACEBOOK SAMPLES:

Option 1: Greater public awareness of rare diseases is critically needed! If you or a loved one has a rare disease and live in PA, please take the confidential PA Rare Disease Survey today. This will help us to better understand the experiences and needs of Pennsylvanians living with a rare disease so that we can best represent and amplify your voice. You can take the survey at pardac.org/survey/.

Option 2: We are proud to partner with the Pennsylvania Rare Disease Advisory Council (PARDAC) to promote the PA Rare Disease Survey. Did you know that 1 in 12 Pennsylvanians are living with a rare disease? We are calling on our members to help us gain more insights into the needs of people living with rare diseases. If you have a rare disease or care for someone who does, please take the survey now at pardac.org/survey/.

Option 3: Do you have a rare disease or care for a loved one that does? Then please invest a few minutes to take the confidential PA Rare Disease Survey. Your responses will help the Pennsylvania Rare Disease Advisory Council (PARDAC) to better understand your unique needs so they can better advocate for you and improve the quality of life for all those affected by rare disease in PA! You can take the [survey](https://pardac.org/survey/) at pardac.org/survey/.



TWITTER SAMPLES:

Option 1: Greater public awareness of rare diseases is critically needed! If you or a loved one has a [#raredisease](#) and live in PA, please take the confidential PA Rare Disease Survey today at pardac.org/survey/ and amplify your voice [#PARareDisease](#) (add your own hashtags).

Option 2: We are proud to partner with the Pennsylvania Rare Disease Advisory Council to promote the PA Rare Disease Survey. 1 in 12 Pennsylvanians live with a rare disease - If you have a [#raredisease](#) or care for someone who does, please take the survey at pardac.org/survey/.

Option 3: Do you have a [#raredisease](#) or care for a loved one that does? Then please take the confidential PA Rare Disease Survey to help [@pararedisease](#) better understand your unique needs so they can better advocate for you! Take the survey at pardac.org/survey/ [#PARareDisease](#).



INSTAGRAM SAMPLES:

Option 1: Do you have a rare disease or care for a loved one that does? Then please invest a few minutes to take the confidential PA Rare Disease Survey. Your responses will help the Pennsylvania Rare Disease Advisory Council (PARDAC) to better understand your unique needs so they can better advocate for you and improve the quality of life for all those affected by rare disease in PA! You can take the survey at pardac.org/survey/

Option 2: Greater public awareness of rare diseases is critically needed! If you or a loved one has a rare disease and live in PA, please take the confidential PA Rare Disease Survey today. This will help the PA Rare Disease Advisory Council to better understand the experiences and needs of Pennsylvanians living with a rare disease so that they can best represent and amplify your voice. Take the survey at pardac.org/survey/

Option 3: We are proud to partner with the Pennsylvania Rare Disease Advisory Council (PARDAC) to promote the PA Rare Disease Survey. Did you know that 1 in 12 Pennsylvanians are living with a rare disease? We are calling on our members to help the PARDAC gain more insights into the needs of people living with rare diseases. If you have a rare disease or care for someone who does, please take the survey now at pardac.org/survey/

Use these hashtags with your posts:

[#PARareDisease](#)

[#RareDisease](#)

[# \(insert your hashtags\)](#)

SECTION B:

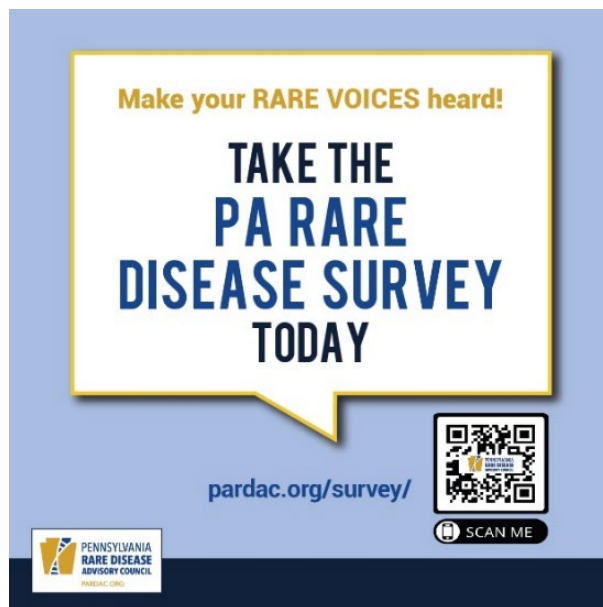
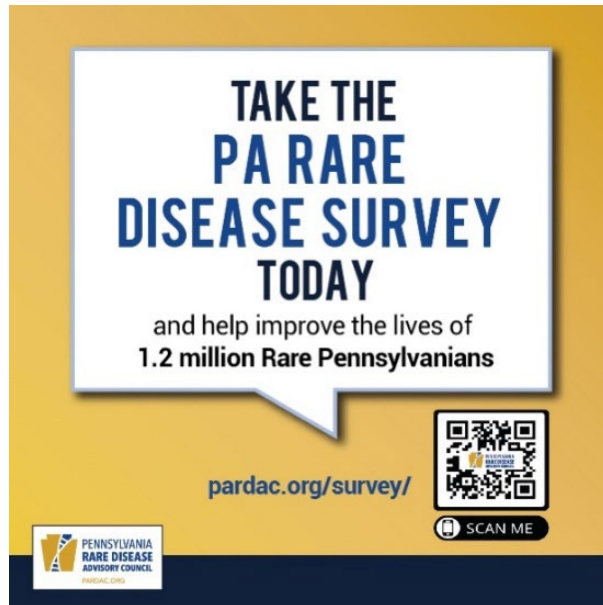
Website and Newsletter Content

PLEASE TAKE THE PA RARE DISEASE SURVEY TODAY!

(Insert organization name) is partnering with The Pennsylvania Rare Disease Advisory Council (PARDAC) to promote participation in the PA Rare Disease Survey. The survey results will help the PARDAC and all of us who support people living with rare diseases to better understand their needs and take action to improve their lives. The survey is completely confidential and takes less than 10 minutes to complete. If you are a rare Pennsylvanian or care for someone who is, please take the [PARDAC Survey](https://pardac.org/survey/) at pardac.org/survey/. For more information about the PARDAC or if you would like information about the survey results once released, please sign up for their [newsletter](https://pardac.org/news/) at pardac.org/news/

SECTION C: Sample Graphics

Note: please use these graphics to accompany your social media posts, newsletter articles, e-mail communications, etc. Please feel free to use other images that resonate with your membership/constituency as well.



There are approximately
7,000
rare diseases afflicting nearly
30 million
Americans.

If you are one of them and live in PA,
we want to hear from you.



**TAKE THE
PA RARE DISEASE
SURVEY TODAY**

It takes **10 minutes** and
is **completely confidential**.



pardac.org/survey/

**1.2 million
Pennsylvanians**

live with a rare disease.

In the U.S., about 30 million people—
50% of them children—have a rare disease.



**TAKE THE
PA RARE DISEASE
SURVEY TODAY**

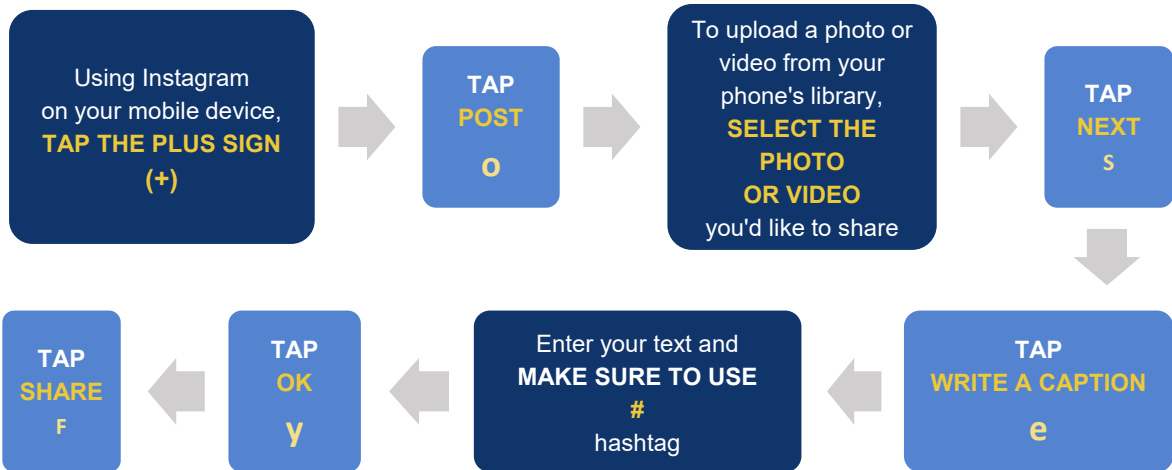
It takes **10 minutes** and
is **completely confidential**.



pardac.org/survey/



UPLOADING A PHOTO OR VIDEO TO INSTAGRAM



UPLOADING A PHOTO OR VIDEO TO FACEBOOK



CREATING A MEME

