

Diagnosis Drives Action toolkit for patient advocacy organizations

Welcome to the Diagnosis Drives Action Toolkit, and thank you for being part of this powerful collaboration across the rare disease community! A genetic diagnosis can end years of uncertainty and wondering, and replace it with hope, clarity and a path forward. **And together, we can ensure this powerful message reaches the countless families still seeking answers and a community of support.**

Introduction to the Toolkit

This toolkit includes ready-to-use co-branded social media resources that you can customize and share to help raise awareness of the power of genetic testing and the impact it has had for the many families your organization supports.

GeneDx Social Media Channels

Facebook: [@GeneDxLab](#) **LinkedIn:** [@GeneDx](#) **Instagram:** [@genedxlab](#) **X:** [@GeneDx](#)

Official Hashtags

#GeneDx #DiagnosisDrivesAction

Tagging Guidelines - how to tag GeneDx

On LinkedIn:

- In your post, type @GeneDx and select GeneDx (Company) from the dropdown
- Make sure you see the name hyperlinked in blue once it posts- confirming the tag worked!
- Optional: Add #GeneDx or #DiagnosisDrivesAction to reach more of the community.

On Instagram:

- In the caption, type @GeneDxLab.
- You can also tag us in the photo itself by tapping “Tag People” before posting.
- Feel free to use #GeneDx or #DiagnosisDrivesAction

Editing assets in Canva

1. Open the [Canva template](#).
2. Click File -> Make a Copy to create your own editable version. Do not edit the original template.
3. Click on the text box and replace the existing placeholder text with your own content.
4. To add your image, select Uploads from the left-hand menu in Canva.
5. Click Upload Files and choose the image(s) from your computer.
6. Drag the uploaded image into the designated image area in the template. Adjust the image as needed so it fits properly.
7. Review your text and image to make sure everything is accurate and positioned correctly.
8. When finished, click Share to send a link or Download to save the completed design.

 **Link:** [Editable Canva template, LinkedIn banner](#)

Important: Please don't change fonts, colors, layout, or other design elements. Only update the text & replace the image.

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Social Example Posts

These examples are meant to spark ideas and don't need to be copied word for word. Make your post personal to your community and share how genetic testing has made an impact, what it has made possible, and how diagnosis can drive action to inspire others.

SHORT copy

For families lost in the diagnostic odyssey, every day without answers is heartbreaking.

But together with #GeneDx, we believe a #DiagnosisDrivesAction and can provide families with clarity, hope, and a path forward.

What's one thing a genetic diagnosis changed for your family, your patients, or your perspective on rare disease?

Share your experience or learn how to access testing at Genedx.com/diagnosis-is-action

MEDIUM copy

For families affected by rare disease, the journey to answers can take 4-5 years, but with genetic testing, families could get answers in just weeks.

Together with #GeneDx, we believe a #DiagnosisDrivesAction and we want to help more families learn about the role genetic testing can play in ending the diagnostic odyssey and creating a clearer path forward.

If you're a clinician who has helped a family find answers, a parent or caregiver whose child received a genetic diagnosis, or a family still searching, we'd love to hear from you.

Here's how you can help:

- Comment below or share this post and share what a genetic diagnosis changed for you, your family, your patients, or your community.
- Visit Genedx.com/diagnosis-is-action to learn how to talk to your doctor about genetic testing or share your diagnosis story to inspire others.

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LONG copy

For many families affected by rare disease, the journey begins with uncertainty.

Questions without answers. Symptoms without an explanation.

On average, families spend 4-5 years navigating appointments, referrals, and testing while searching for a reason why.

The diagnostic odyssey can be long, frustrating, and isolating. But a genetic diagnosis can change what happens next.

It can help families better understand their child's condition, make more informed care decisions, access support and resources, and connect with others walking a similar path. For many families, it's the moment uncertainty becomes understanding.

That's why together with our friends at #GeneDx, we're starting a conversation around a simple belief that a #DiagnosisDrivesAction

Every answer has the potential to create new possibilities, whether that's a treatment decision, a care plan, access to support, or simply the confidence that comes from knowing.

Together, let's raise awareness of the power of genetic testing and help more families affected by rare disease find answers sooner.

Whether you are:

- ♥ A clinician who has helped a family find answers
- ♥ A parent or caregiver whose child received a genetic diagnosis
- ♥ An advocate working to improve rare disease awareness and access
- ♥ A family still searching for answers

Here's how you can help:

- Comment below or share this post and share what a genetic diagnosis changed for you, your family, your patients, or your community.
- Visit Genedx.com/diagnosis-is-action to learn how to talk to your doctor about genetic testing or share your diagnosis story to inspire others.



Thank you for your support.