



## Rare Drug Development 2024 Media Kit

Innovative Ideas from Next Generation Change-Makers

The RARE Drug Development Symposium (#RDDS), hosted by Global Genes and the Orphan Disease Center of the University of Pennsylvania, equips advocates with the knowledge, skills and connections they need to advance therapy development for their communities. This media kit is designed to assist you in sharing this event with your network. We hope to see you in Philadelphia this year!

Follow Global Genes on social media (@globalgenes) for #RDDS updates



Follow ODC accounts



Content Included:

- Event Information and URL
- Global Genes and Orphan Disease Center Social Media Accounts
- Social media language that you can copy and paste to share on your accounts
- Links to social media posts from Global Genes that you can easily reshare or retweet
- [Images to use on social media and in emails](#)
- Email copy to use in your newsletters or emails
- Media Language

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Event Information

Webpage: <https://go.globalgenes.org/rdds2024>

Summit name: RARE Drug Development Symposium

Summit Date: April 29 - May 1, 2023

Summit Location: Sheraton Philadelphia Downtown, North 17th Street, Philadelphia, PA

Hashtags to use: #RDDS #CareAboutRare #RareDisease #GlobalGenes #ODCUPENN

Tag: @globalgenes @mdbride4rare @ODC\_UPenn

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## Social Media Language

RDDS images to accompany your social media post can be accessed [here](#).

General Post #1: RARE Leaders Don't Want To Miss This Event! The RARE Drug Development Symposium is designed to empower advocates like you to become next-generation change makers in the field of rare disease drug and therapy development. Learn more about #RDDS here: <https://go.globalgenes.org/rdds2024> #RDDS #CareAboutRare

(Org) We're Attending: We're looking forward to joining @globalgenes and @ODC\_UPenn at the RARE Drug Development Symposium. Join us and other advocates as we worked toward enhancing and improving the world of #RareDisease drug and therapy development. #RDDS #CareAboutRare

(Individual) I'm Attending: I'm looking forward to joining @globalgenes and @ODC\_UPenn at the RARE Drug Development Symposium. Join me and other advocates as we worked toward enhancing and improving the world of #RareDisease drug and therapy development. #RDDS #CareAboutRare

## Email Language

RDDS images to accompany your email post can be accessed [here](#).

### Email (Short)

*Hi,*

*In our fast-evolving world, where innovation and advocacy play pivotal roles in shaping the future, we believe it is essential for individuals like you to be at the forefront of change. That's why Global Genes and the Orphan Disease Center of the University of Pennsylvania annually host the RARE Drug Development Symposium (RDDS). This event is designed to empower advocates like yourself to become next-generation change makers in the field of rare disease drug and therapy development. This year's event is focused on bringing unique features to enhance advocates' understanding of the drug development path and provide them with resources.*

*Register below to attend April 29-May 1 in Philadelphia, PA!*

*CTA: Register Here*

### Email (Long)



Hi,

*In our fast-evolving world, where innovation and advocacy play pivotal roles in shaping the future, we believe it is essential for individuals like you to be at the forefront of change. That's why Global Genes and the Orphan Disease Center of the University of Pennsylvania annually host the RARE Drug Development Symposium (RDDS). This event is designed to empower advocates like yourself to become next-generation change makers in the field of rare disease drug and therapy development. This year's event is focused on bringing unique features to enhance advocates' understanding of the drug development path and provide them with resources.*

*Register below to attend April 29-May 1 in Philadelphia, PA!*

*CTA: [Register Here](#)*

*Aside from innovative keynote and session topics, key interactive highlights, this year the event brings more interaction sessions for participants to get the most out of their experience. This includes:*

- *Group sessions will allow you time to engage with experts and peers in small groups to discuss session topics further, innovations in rare drugs, and therapy development process.*
- *One-on-One Expert Office Hours are back by popular demand! Get answers to your questions by scheduling a one-to-one session with one of our experts on topics such as data collection, research strategy, therapy development, and engaging with the FDA. Lunch and Facilitated Table Topics will allow you time to enjoy lunch over conversations with those who are interested in similar topics. Specific topics will be labeled by table and facilitated by an expert.*
- *Rare Resource Fair is new this year! Whether you're creating a research strategy - or putting an existing one into action, this session will help you build knowledge, ask providers of products and services the questions you have about your specific situation, and make informed decisions on which companies you want to work with. If you're new to research, you can request a mentor to guide you through the fair.*



## For Media Use:

Global Genes and the Orphan Disease Center of the University of Pennsylvania are hosting their annual RARE Drug Development Symposium (RDDS), April 29-May 1, 2024 in Philadelphia, PA. This event is designed to empower advocates to become next-generation change makers in the field of rare disease drug and therapy development and equip them with the knowledge, skills and connections they need to advance therapy development for their communities. This year's theme is Innovative Ideas from Next Generation Change-Makers.

This year's event focuses on bringing participants interactive opportunities to collaborate and meet with experts and other advocates. This opportunities include unique features like:

- Group sessions will allow participants time to engage with experts and peers in small groups to discuss session topics further, innovations in rare drugs, and therapy development process.
- One-on-One Expert Office Hours are back by popular demand. Participants can schedule one-to-one 15 minute sessions with an expert on topics such as data collection, research strategy, therapy development, and engaging with the FDA.
- Lunch and Facilitated Table Topics will allow participants time to enjoy lunch over conversations with those who are interested in similar topics. Specific topics will be labeled by table and facilitated by an expert.
- Whether an attendee is creating a research strategy or putting an existing one into action, Rare Resource Fair will help them build knowledge, ask providers of products and services the questions about their specific situation, and make informed decisions on which companies to work with. If they are new to research, they will be able to request a mentor to guide them through the fair.

Learn more about RDDS [here](#).

## About Global Genes

Global Genes is a 501(c)(3) nonprofit organization dedicated to eliminating the burdens and challenges of rare diseases for patients and families globally. In pursuit of that mission, Global Genes connects, empowers, and inspires the rare disease community to stand up, stand out, and become more effective on their own behalf — helping to spur innovation, meet essential needs, build capacity and knowledge, and drive progress within and across rare diseases. Global Genes serves more than 400 million people around the globe, and nearly one in 10 Americans affected by rare diseases. If you or someone you love has a rare disease or are searching for a diagnosis, contact [Global Genes](#) at 949-248-RARE or visit the [Resource Hub](#).



### **About Orphan Disease Center of the University of Pennsylvania**

The Orphan Disease Center will develop transformative therapies using platform technologies that can be deployed across multiple rare diseases. We will emphasize disorders with substantial unmet need independent of their incidence and will strive to assure access to patients of all populations. Each type of orphan disease affects such a small subset of the population, so the need for research and funding in this area is largely unmet. Our Center, the first of its kind, works closely with patient groups and foundations, pharma and biotech, and the academic community. We bring a unique set of programs to the table, enabling us to add value at any stage - from building the initial knowledge base to enabling therapeutic development. Through our grants, Programs of Excellence, JumpStart programs, and a number of new initiatives, the ODC seeks to drive therapeutic development for rare diseases. We help identify and fund the most promising therapeutics while also tackling obstacles present in rare disease drug development.