Global Genes Live! A Rare Patient Advocacy (un)Summit

Navigating Your Virtual Event Experience

GlobalGenes.org/live
Welcome to Global Genes LIVE! A RARE Patient Advocacy (un)Summit. Normally, we’d be welcoming you in person to sunny San Diego, California, but in the interest of the health and safety of our community, we have chosen to do something a little different this year.

While we will be sharing scientific updates, opportunities for you to connect and network with others in the community, and inspiring keynotes, we also wanted to bring in some lighter experiences with an evening of entertainment, rare disease film watch parties and more. We know that for many of you, our annual gathering is a source of inspiration and rejuvenation. We hope that, even with all that is going on in the world right now, we can still be that bright spot for you.

As a global pandemic has dominated our lives for most of the year, it has also created opportunities for change that could benefit the rare disease community. From embracing telehealth to changing U.S. Food and Drug Administration (FDA) guidelines for clinical trials, there is a lot to unpack during our panel discussions this year.

To help you get the most out of your virtual event, we have created this simple guide. But as always, if you have additional questions, please do not hesitate to reach out to our team at events@globalgenes.org.
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HOW TO WATCH SESSIONS

All sessions can be accessed via the virtual event guide and event mobile app.

- To access the virtual event guide, please enter the following URL into your web browser `https://event.crowdcompass.com/globalgeneslive`.
- To download the mobile app, please scan the QR Code below or type the following URL into your web browser on your mobile device or tablet `https://crowd.cc/s/3Tb9W`.

You can access all sessions through the “All Sessions” tab within the virtual event guide. Once you click on a session, there will be a button for you to click on to access the session.

Sessions taking place on September 21-25 will be run on the ON24 platform and will require you to sign in to enter the event. If you did not select the specific session when you registered, you can still attend by doing a simple registration at time of entrance to the event.

All sessions can be attended using a laptop, desktop, mobile device, or tablet.
VIRTUAL EVENT GUIDE AND MOBILE APP

The virtual event guide and mobile app are where you can access everything you need to participate in Global Genes LIVE! A RARE Patient Advocacy (un)Summit. To access the virtual event guide, please enter the following URL into your web browser https://event.crowdcompass.com/globalgeneslive. To download the mobile app, please scan the QR Code below or type the following URL into your web browser on your mobile device or tablet https://crowd.cc/s/3Tb9W.

How to Access the Event

https://youtu.be/mRwuhvRk9bE

How to Navigate the Event

https://youtu.be/8TRIM_fmAwa
**Edit Your Event Schedule**
Make sure you don't miss anything by managing your schedule.
1. To edit your schedule, click on the agenda icon. There will be two tabs, one that shows all sessions and one that only shows the sessions selected during registration.
2. If you want to add a session to your schedule find the session you would like to add and click on the plus button to the right of the session title.
3. If you want to remove a session, click on the green check mark button to the right of the session title.

**Manage Activity Feed**
If you click on the activity feed icon within the virtual event guide or mobile app, there will be two tabs, one for the event feed and one for the social wall.
- The event feed displays in-app posts and comments within your app's activity feed.
- If you want to post in the event feed, click on the grey post button in the top right corner of the event feed page.

**Getting Social**
- The social wall aggregates social posts from twitter
- Please use #2020GGSummit when posting photos or posts. Anything posted using this hashtag will filter into the social wall.
- To access the Facebook photo frame
  1. Go to this url to add a frame to your profile photo
     www.facebook.com/profilepicframes/
  2. In the search bar type in “Global Genes Live”
  3. Resize your photo to fit, and drag to desired position
  4. Select time frame from “Switch back to previous profile picture in …”
  5. Click “Use as Profile Photo”

**Manage Your Profile**
How much you share about yourself with other attendees is up to you. You have the ability to update your information as well as hide your contact information or make it visible to others.

**Hiding Contact Information**
1. Access your profile settings.
2. Switch your profile visibility to hidden in order to hide your contact information such as your email address and phone number.
3. Attendees will still be able to view your name, title, company, bio and picture

**Hide Completely from Other Participants**
1. Click on the Attendees icon.
2. Click on the Profile Options in the top right corner and select “Hide on Attendees List”

**Update Information**
1. When you enter into the virtual event guide or the mobile app, you will be prompted to first update your attendee profile.
2. You can update your profile at any time by accessing your profile settings.
In addition to the fun entertainment experiences and informative panels, we encourage you to connect with fellow participants in two ways. All networking opportunities will remain open to you until October 2, 2020.

https://youtu.be/Yg6H8r__-Z8

**One-On-One Messaging**
This feature is available within the virtual event guide and the mobile app.

**Send a Message**
1. Tap on the Attendees icon.
2. Find the person you would like to message and tap on their name.
3. In their profile, tap the message icon.
4. Write your message, then tap Send.

**Checking Your Messages**
1. To check if you have any messages, look for My Messages in the side nav.
2. If you have a message, there will be a red circle with the number in it.
3. Tap My Messages to see who's contacted you.

**Slack Networking Hub**
Giving you an opportunity to network with the larger group of participants, we are offering you networking through Slack with pre-determined networking channels for you.

1. Prior to the event you will receive an invitation to the Global Genes LIVE! Slack group. In order to participate in this networking, you must join the slack group
2. Once you have joined you can keep the slack open on your desk top or download the slack mobile app
3. This will take you to the Global Genes LIVE! Slack group

**Here are the links to join the Slack community:**

If you have not joined the Global Genes LIVE! Slack community yet, click here to join.
https://globalgeneslive.slack.com/join/shared_invite/zt-h2w2es7p-CmKV9lpvx6A8H8M5Ccrxg#

If you have already joined the Slack community, click here to sign in.
https://globalgeneslive.slack.com/join/shared_invite/zt-h2w2es7p-CmKV9lpvx6A8H8M5Ccrxg#
TIPS FOR A SUCCESSFUL VIRTUAL EXPERIENCE

We know that attending a virtual event can be an adjustment for participants. We have compiled a list of tips to help you get the most out of your virtual event experience.

• **Test Your Tech:** Before the event, make sure that your chosen device is working properly, fully charged, and has wifi access. We will do everything on our end to ensure a great experience and we don't want you to miss a thing. If you experience an issue, please email us at events@globalgenes.org.

• **Connect with Others:** We encourage you to take advantage of networking tools to see who is participating and connect with them. This will help you to get more out of your experience while also growing your personal network.

  If you are active on social media, follow the event hashtag – #2020GGSummit. We'd love to have you join the conversation as we post about key takeaways, event highlights and more.

  And don't let the networking stop when the event stops. We encourage you to trade contact information and connect with fellow participants on other platforms such as LinkedIn or Facebook or simply by email.

• **Ask Questions:** The event offers many opportunities to engage with the content and get your questions answered by the presenting experts. This event is meant to help you foster cross-geography and cross-functional learning and break down knowledge silos, so don't be shy about taking advantage of this moment to learn everything you can. We want you to come out of this being able to apply what you've learned immediately.

• **Minimize Distractions:** When attending a virtual event, it can be easy to start multi-tasking and become distracted. To get the most out of the sessions, close your email and block off your calendar so you can focus on the presenters and engage in the Q&A opportunities.

• **Be a Winner:** Adding a little competition to your virtual event, as you explore the mobile app, you'll earn points and achievements. You can even opt in to compete on the leaderboard against other event attendees. You never know who will be right on your heels! Play along by following the steps below.
  » Click on the Game icon
  » Under the “My Progress” tab you will find different tasks to complete. Each task is worth a different amount of points
  » As you complete tasks, you will receive automatic notifications that you have completed the task and have been awarded points
  » You can view your points in the “My Progress” tab and see how you compare to others in the “Leaderboard” tab

• **Your Feedback is Wanted:** Please take a few moments after each session to give us feedback on your experience. You can provide us feedback in the virtual event guide and mobile app by following the following steps below.
  » After the session ends, click on the Surveys icon
  » Click on Session Feedback
  » Select the session survey you would like to take and complete the survey
Thank you to our 2020 RARE Patient Advocacy (un)Summit Advisory Committee

Thank you to the rare disease leaders and advocates who have contributed to shaping the agenda content! We appreciate the ideas and insights that you have shared with us and the community.

Jocelyn M. Ashford, *Eidos Therapeutics*

Todd Bledsoe, *Neurocrine Biosciences*

Anne Bruns, *PTC Therapeutics*

Tiffany Cook, *Cure Duchenne*

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Jennifer Siedman, *Courageous Parents Network*
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UPCOMING EVENTS

RARE Champions of Hope
– November 12, 2020

World Rare Disease Day
– February 28, 2021

RARE Drug Development Symposium
– June 2021

RARE Patient Advocacy Summit
– September 2021