

You're Invited to the RAREly Told Stories filmmaking workshop

You are invited to participate in an exclusive workshop with The Disorder Channel and could win a trip to have your film screened at our Patient Advocacy Summit in September or our RARE Health Equity Summit in November!

If you've been wanting to tell the story of your experience with a rare disease, the **RAREly Told Stories Workshop** can help you learn to document your journey. If you have any questions please don't hesitate to reach out to us at danield@globalgenes.org.

We're excited to hear your story.

What is the RAREly Told Stories Workshop?

One of the most impactful ways to tell your story is through video and film-making. As parents to children with rare diseases, Bo Bigelow and Daniel DeFabio founded The Disorder Channel and Disorder: The Rare Disease Film Festival in order to amplify the individual stories and voices of the rare disease community to improve access to quality care. Through their efforts they have been able to bring increased attention to more than 150 rare diseases.

Global Genes is thrilled to be partnering with The Disorder Channel, which will host a unique virtual workshop for advocates to improve their skills in documenting their journey and highlighting their perspective of rare diseases. The workshop is your chance to learn the basics of film or video production from award winning rare disease filmmakers. You will learn what to shoot, how to shoot it, and how to edit it into your finished video.

This 1-hour virtual workshop will be held twice - once in May and once in June - with The Disorder Channel founders and other rare disease filmmakers. Following the workshop, participants can connect with the filmmakers on a one-on-one basis to help refine their documentary. Selected films will then be chosen to be showcased at the Patient Advocacy Summit in September or at the RARE Health Equity Summit in November and through other Global Genes communications.

Do I need to have prior film experience to attend?

No, you do not. The workshop is geared towards beginners and we highly encourage everyone to attend regardless of prior filmmaking experience.

When will the RAREly Told Stories filmmaking workshops take place?

May 31, 2022 12pm - 1pm EST

June 29, 2022 7pm - 8pm

Are the workshops in person or virtual?

The workshops will be held virtually via zoom.

Do I need to attend both workshops to make the film?

No, the same information will be presented at both workshops, so you only need to attend one in order to make a film and submit it to be screened at either the Patient Advocacy Summit in September or the RARE Health Equity Summit in November.

What if I can't attend either of the dates but still want to make a film?

Members of our RARE Portal can view the workshop as an on demand video. On rarecommunity.org check the top nav bar under BROWSE for Rarely Told Stories. If you are able to complete your film by our deadlines we welcome you to submit them.

Will my film be screened at one of the Global Genes Summits?

We will be showing 3-5 films at each of the Summits (Patient Advocacy in September and Health Equity in November). Once all films are submitted, an internal team will review and decide which films will be screened. If your film is selected, you will receive a scholarship to attend the event in person.

In order for your film to be shown at the Patient Advocacy Summit (**September 12 - 14, 2022** in San Diego, California), your film must be finalized and submitted by Aug 15, 2022.

In order for your film to be shown at the RARE Health Equity Summit (**November 9 -11, 2022** in Atlanta, Georgia), your film must be finalized and submitted by October 1, 2022

Technical Requirements

Some of you may want to start shooting footage for your film before the workshop. There are two basic types of shots you'll want:

1. the interviews (someone talking to camera) and
2. the b-roll or lifestyle footage.
 - » B-roll are scenes from your daily life that can be used with or without sound in your film. We often see them while the sound from the interview continues. For example in the interview if going to the hospital is mentioned, it's great to have b-roll of walking up to the front entrance of the hospital.

Tips and tricks for shooting:

» Be sure to shoot everything with your phone or camera horizontal (landscape mode) not vertical.

» Your videos should be 1920x1080 pixels (1920 in horizontal). Larger formats are also acceptable. Finished videos should be **between 3 and 10 minutes long**.

» Anyone who appears in your video will need to sign an appearance release form. You will probably want to avoid shooting large groups for this reason. Parents will need to sign for those under 18 years old.

You should record many more video clips of both interviews and b-roll, described above. These will become the scenes you edit together into a short video. In other words don't wait for the workshop, instead start filming material on a regular basis that you'll want to use later in your finished video.

Resource Links

(Some of these refer to recording on Zoom, but your cell phone is usually a higher quality option)

- » [Tips For Making Videos During A Pandemic Lockdown](#)
- » [How To Make Your Own Rare Disease Film](#)
- » [Using Storytelling To Raise Awareness For Your Rare Disease](#)
- » [Speak Easy: A Guide to Public Speaking](#)
- » [Rare On The Road March 2021 webinar video](#) -- You can skip to 17 minutes through 39 minutes to hear filmmaker Daniel DeFabio and podcaster Effie Parks offer strategies on telling your rare story. You must log in to the RARE Portal before using the next two links.
- » [How to interview well on Zoom - for interviewees](#)
- » [How to interview well on Zoom - for interviewers](#)
- » For questions contact danield@globalgenes.com.

About the Patient Advocacy Summit

Global Genes is excited to celebrate our 11th Annual RARE Patient Advocacy Summit in 2022! The RARE Patient Advocacy Summit has grown to be one of the world's largest gatherings of rare disease patients, caregivers, advocates, and stakeholders. This is an unparalleled opportunity to forge meaningful connections with others in the rare disease community for future collaboration. Sessions provide attendees with insights about the latest in rare disease innovations, best practices for advocating on an individual and organizational level, and actionable strategies they can take home and implement immediately to accelerate change. This year, the Summit will be held as a hybrid event, with meetings, workshops, and sessions held in **San Diego, California** and educational sessions live-streamed online.

About the RARE Health Equity Summit

The RARE Health Equity Summit was developed in order to gain a better understanding of the persistent gaps that exist in the rare disease community for underrepresented and/or minoritized patient populations, including those who are still seeking a diagnosis or are unaffiliated with a disease-specific foundation.

Presented in partnership with the Rare Disease Diversity Coalition (RDDC), the RARE Health Equity Summit connects stakeholders from the rare disease community, including our RARE Health Equity Leadership Council, to find ways to collaborate on how to address inequities in the care of patients with rare diseases. Sessions may focus on shortening the diagnostic odyssey, reducing racial disparities in care, and building more inclusive research programs.

Through the outcomes and learnings of these efforts, we will be able to provide more accurate and relevant resources and information to underserved and underrepresented patient communities.

In **November**, Global Genes will convene approximately 100 stakeholders in Atlanta, Georgia, across the rare disease community including healthcare professionals, patient advocates, industry, researchers, and policy makers to discuss how to make progress together and bridge inequities of care within the rare disease community.

RAREly Told Stories Workshop participants whose films are selected to be screened will be invited to one of these events. Expenses for travel and lodging will be provided to you if you are invited to participate.

What Should I Talk About?

The video you make can be based on any aspects of your experience with rare disease. If you're in our Rare Compassion Program you can choose to base it on your experience in RARE Compassion with or without your paired medical student or patient. You may have an idea that would work well if both parties appear on camera, only to find out that the patient prefers not to, or the medical student prefers not to. We will still welcome a video from you that includes only your own side of the experience in the program and leaves the other party anonymous.

The topics you cover in your film are your choice, whatever seems important to you. "AHA!" or breakthrough moments are always powerful. It could be helpful to think about a person looking to learn about rare viewing your video. The questions you had in your early days, they will likely have too. Perhaps your video will answer some of those questions.

You don't need to answer these questions, but if they help you to start, consider:

- » What have you been surprised to learn about rare disease?
- » What do you wish more people understood about rare disease?
- » Thoughts you have on how medical education and training might better address rare diseases?