

RARE PATIENT ADVOCACY SUMMIT POSTER ABSTRACT GUIDE

Patient organizations (and patient advocates), academics, researchers, industry, government agencies, and health care professionals are invited to submit a poster abstract for the 2022 Patient Advocacy Summit, scheduled for September 12 – 15, 2022.

THEMES & TOPIC GUIDANCE

For the 2022 RARE Patient Advocacy Summit, poster abstracts can include but are not limited within the following areas of work:

- Collaborative Approaches to Collective Challenges in Rare Disease Research
- Health Equity, Diversity and Inclusion (US or International)
- Financial Advocacy, Financial Literacy, and Burden of the Cost of Care
- Effective and Transformational Advocacy Initiatives/Events
- Technology Tools to Advance or Support the Rare Disease Community
- Supporting Clinical Trials, Research, and Science

- Industry
- Other

We specifically encourage emerging rare leaders, patients, advocates and nonprofits to submit abstracts on their related projects to highlight the great work happening throughout the rare disease community.

KEY DATES & DEADLINES

- Poster Abstract submission period opens **July 5th, 2022**
- Abstracts must be submitted by 5pm ET on **August 1st, 2022**
- Notification of Acceptance will be issued on **August 8th, 2022**

ABSTRACT SUBMISSION DETAILS

Please be prepared to include these materials with your submission:

- Presenting author's contact information
- Poster title and abstract (preferred length under 700 words)
- Brief biography for presenting author (additional presenter bios may be included)

SUBMISSION FORM

Please [complete the form here](#) to submit your abstract for consideration. All submissions must be received by **5pm ET August 1st, 2022** in order to be considered for the 2022 program.

PRESENTER RESPONSIBILITIES

Presenters will incur all costs* and responsibilities of presenting, including registration fees and materials. Presenters must register for the event in order to access the poster booth**. A registration link will be provided upon abstract acceptance.

*Scholarship opportunities may be available for qualified patients, advocates and researchers. Please contact *Nicholas Ehly* at nicholase@globalgenes.org to inquire.

**All posters will be presented in person and virtually.

Presenters are encouraged to attend the in-person program, but if unable to attend may send their poster for display. Contact nicholase@globalgenes.org to discuss arrangements.

ACCEPTED POSTER INFORMATION & POSTER DISPLAY REQUIREMENTS

Accepted posters will need to submit the final materials for presentation by **August 29th, 2022**.

- A poster to be presented digitally (PDF) and in person
 - Posters should include data (summary, method, evaluation, results, demographics, etc.) for consideration
 - Preliminary and pilot data will also be accepted
 - In-person posters should be sized 4 ft by 6 ft, printed and put on boards
 - Posters should be sized for a 16:9 viewing ratio
- A final poster abstract
- Presenting author(s) headshot(s) and short bio(s)

PRESENTATION SCHEDULE

Posters will be available for the duration of the program (September 12 – 14, 2022), including a few days leading up to the program when the virtual platform is opened for attendee orientation.

Specific times for presenter Q&A will be confirmed for accepted poster presenters.

FREQUENTLY ASKED QUESTIONS

Is there an abstract submission fee or other presenter costs?

There is not a fee to submit an abstract. However, accepted poster presenters must register for the event in order to attend and access their poster/booth. Poster presenters may register at the discounted rate of \$75.00* and registration details will be provided upon acceptance.

**If the registration fee presents a barrier to access for you, please reach out to Nicholas Ehly at nicholase@globalgenes.org to discuss potential scholarship opportunities.*

Are there rules about previous presentation of data?

Encore presentations are permitted. All abstracts will undergo review by the Abstract Review Committee for evaluation and acceptance.

Is a trial-in-progress abstract allowed?

Yes

Is there an author limit for abstracts?

No

Is there a word limit or character count to which we should adhere?

Yes, there is a limit of 700 words. Charts and graphs are also acceptable.

What are the Embargo Rules, if any?

None for encores; for primary disclosures, scientific dissemination should be reserved until after the Summit. Press releases and media coverage are allowed in advance of the Summit.

Is there a language requirement for the abstracts?

Abstracts must be submitted in English.

What will be included in the virtual poster booth?

Booths will include your abstract, presenter information, and PDF version of your poster. The virtual poster is for attendee viewing only, there is no interaction between the poster presenter and attendee. Further details on how to upload and make changes will be provided to accepted presenters.

What technology are you using? Is it complicated?

The virtual platform is called Attendee Hub. Further details regarding the platform, login details, and technologies will be available for accepted presenters.

I still have questions, who can I reach out to?

Please contact Nicholas Ehly at nicholase@globalgenes.org for any questions about poster presentations.

Who should the authors be? How do I determine my authors?

For the 2022 Patient Advocacy Summit, it is strongly encouraged that an author or collaborator from a patient advocacy group be listed. Representatives of members of the Global Genes Foundation Alliance are encouraged to apply and be listed as authors.

Why should you create a poster?

Poster presentations provide an opportunity for you to share the work of your organization, team or community with a larger audience of rare disease stakeholders from advocacy, research and industry. Showcasing ongoing or completed projects often can provide new connections/opportunities to meet new collaborators and/or potential funders.

Are there any tips for creating an “attractive” poster/abstract?

- The title of the poster is very important to draw attention, like a good news headline.
- There are powerpoint ppt poster templates available from various sites.
- An abstract is important to attract an audience to review your poster presentation in more detail.
- Make it simple, easy to read, organized and presentable.
- Add a patient picture, story, or perspective as it will make the poster more attractive.

Is there a choice between a virtual display and an in-person display?

No, all posters will be displayed both in person and virtually.

Will I be required to attend in person to present my poster?

We highly encourage you to attend the Patient Advocacy Summit in person, but it is not a requirement. If you are unable to attend in person, please let us know by **August 17, 2022**.

Is there a time to present my poster?

There is no set time to present your poster. However, there will be a time when we ask all poster presenters to be in the events hall to answer any questions about their posters. More details will be provided upon your acceptance.

