

# Event Planning Toolkit



Your Comprehensive Guide to  
Rare Disease Conference Planning



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## Toolkit Overview

This toolkit is your ultimate companion, crafted especially for you, the dedicated leader of patient advocacy groups. Its purpose is to empower you to plan and host impactful patient and research conferences. Within these pages, you will discover a treasure trove of practical resources, templates, timelines, and invaluable insights gleaned from the experiences of fellow rare disease patient advocates.

Our aim is simple: to equip you with the tools and knowledge necessary to confidently plan, execute, and evaluate successful and accessible conferences. With clear step-by-step instructions, best practices, and customizable tools, you will find it a breeze to navigate the complexities of event planning, allowing you to deliver meaningful experiences for your community.

But this toolkit is more than just a guide—it is a call to action. It is an opportunity for you to bring people together, to share knowledge, and to inspire change. By using this resource, you are not just organizing an event, you are laying the groundwork for transformation, advocacy, and connection.

Remember, event planning is about fostering community and creating lasting impressions. Trust your instincts, embrace your unique approach, and enjoy the journey. Your event will be extraordinary because it is driven by your passion for uniting your community and advancing our shared mission.

**Let's create events that leave a lasting impact  
and drive progress toward a brighter future.**

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## Section

# 1 Pre-conference Planning

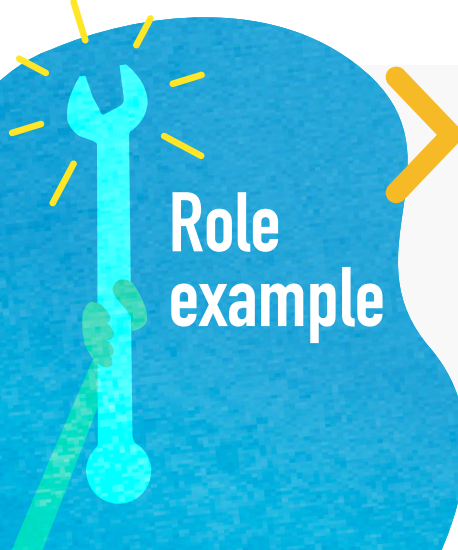
## Appoint a **Conference Planning Committee**

Planning is the key to success and will ensure that you make the most of your resources and guarantee a successful event. To create an impactful conference, tap into the insights of key stakeholders. **Consider kicking things off by establishing a planning committee that includes:**

- > **Board members from your organization**
- > **Patients**
- > **Family members**
- > **Volunteers**

Having **a mix of individuals** ensures a robust input of ideas and a manageable distribution of the workload. Different members of the committee can focus on specific areas, such as panel content, marketing, food and hospitality, logistics, and attendee engagement, ensuring that all aspects of the conference are well-covered.

The planning committee should be tasked with defining conference objectives, determining the meeting format (in-person, virtual, hybrid), identifying the target audience, and deciding whether the conference will focus on family education, community engagement, networking, and/or research collaboration. This comprehensive approach guarantees a well-rounded and organized event. >> See the **“Resources”** section for a sample event planning template that your planning committee can use to help keep planning on track.

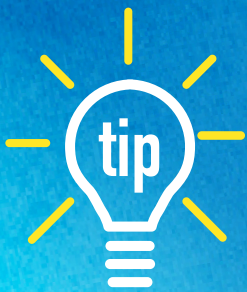


## Role example

**Consider including an accessibility chair role on the planning committee.** This person would be responsible for ensuring that the conference is as welcoming and accessible as possible. Tasks might include working with attendees and speakers to understand and help meet their needs, serving as an advocate for attendees with disabilities, and serving as a liaison between attendees and the conference organizers.

## Conduct a Needs Assessment

Assessing the specific needs and interests of your community can help to inform decisions on conference content. If time permits, a needs assessment can be conducted with surveys or focus groups in online, in-person, or hybrid formats. Soliciting feedback from community members on their preferred focus for the conference (scientific content, family focused, or both), their preferred topics, their preferred formats (in-person, virtual, hybrid), and any accessibility needs can provide valuable information for the conference planning phase. Be sure to also ask for preferences on specific dates and event locations.



**“Use focus groups or interviews for in-depth discussions with community members who may have unique perspectives.”**

*— Patient Advocacy Group Member*

## Choose the Right Format for Your Conference

The meeting format should be carefully considered by the planning committee to ensure a seamless and engaging experience for attendees.

If your community expresses a strong interest in networking, an objective of your conference could be to facilitate meaningful connections between attendees through family-based activities. To facilitate planning, it is important to define clear objectives for your conference, such as increase awareness, provide educational resources, foster collaboration, and connect families with researchers.

**There are typically three main types of conferences:**

**1. Families**

**Goal:** To provide support, education, and community for families affected by rare diseases

**Audience:** Patients, family members, caregivers, and patient advocacy groups

**2. Researchers**

**Goal:** To share the latest research findings, foster collaboration, and advance scientific understanding of rare diseases

**Audience:** Researchers, scientists, medical professionals, and academic institutions

**3. Families and Researchers**

**Goal:** To bridge the gap between families and the scientific community, facilitating collaboration, and fostering a comprehensive approach to rare disease challenges

**Audience:** A mix of patients, families, caregivers, researchers, medical professionals, and advocacy groups

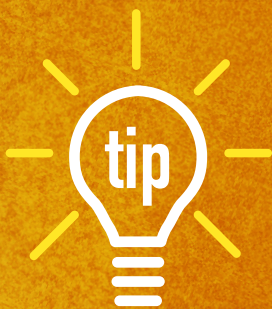
## In-Person and Online Conferences

The spaciousness and accessibility of the venue, as well as proactive communication with attendees regarding event logistics, contribute to successful in-person conferences. You also need to consider the presentation format—panel presentation, solo speaker—as this will help determine what venue is most suitable. Consider the setup of the seating arrangement. Do you need a stage? Do you want the attendees to sit at tables or just at chairs? If tables are used, consider whether rounds that encourage communication or classroom rows facing the front would be more effective.

Virtual formats require a user-friendly interface and live technical support to troubleshoot any issues attendees, speakers, and conference organizers might encounter. Gamification or interactive elements could help to improve engagement throughout the conference.

Key considerations for conferences that include both virtual and in-person formats (hybrid) include selecting an appropriate venue and integrating in-person and virtual components effectively, ensuring smooth transitions between the two.

Specific services to support virtual and hybrid meetings include video conferencing platforms like Zoom, Microsoft Teams, and Google Meet; collaboration tools, such as Slack or Asana; and engagement software like Mentimeter or Slido. Virtual event platforms like Hopin, Cvent, and Remo offer comprehensive solutions for large-scale, online conferences, with live streaming and interactive features for audiences.



**“Remember that a successful conference is not one size fits all, so be sure to define what success would look like for your advocacy organization.”**

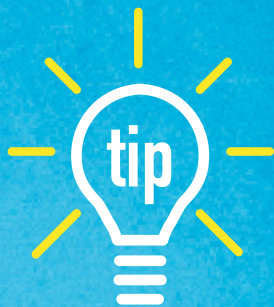
*— Patient Advocacy Group Member*

## Create a Budget

In the early stages of conference planning, it is important to develop a comprehensive budget that covers all aspects of the conference from the cost of the venue to marketing expenses.

**>> See the “Resources” section for a sample budget template that you can customize for your specific needs.**

Identify your maximum budget, maximum number of attendees, and other key factors that are specific to your conference. If you reach your budget limit or costs are too prohibitive, consider transitioning to virtual or hybrid formats with audiovisual (AV) support.



When selecting a venue for in-person meetings, it's crucial to consider whether a certificate of insurance (COI) is required, as this can increase costs. **To manage expenses, explore discounted or donated services** through platforms like TechSoup for technology needs and seek collaborative partnerships or donations from local businesses.

Be mindful of potential hidden costs, such as grant application fees and technology upgrades, to ensure the conference is well-budgeted and successful.

**>> See more funding tips in the “How to Raise Money for Your Conference” section.**





## Event Planning Considerations >

Regardless of the meeting format, be sure to include line items for marketing, promotion, and attendee engagement strategies. This could mean budgeting for a photographer or videographer to capture key moments for promotional and archival purposes.

If possible, consider creating a speaker honorarium fund to show appreciation for the time and expertise provided by your speakers. Also, consider including a contingency fund line item for unexpected expenses and fluctuations in attendance.



**“For live streaming events, be sure to include costs for a hardwire network connection at your preferred speed.”**

— Patient Advocacy Group Member

## Potential Budget Considerations by Meeting Format

Meeting Format	Expenses
<b>In person</b>	Venue rental Catering Transportation On-site staff Audiovisual support
<b>Virtual</b>	Video conference platform Virtual event software Real-time technical support for hosts and attendees
<b>Hybrid</b>	All of the above expenses plus Audiovisual live streaming support Accommodation for remote participation tools

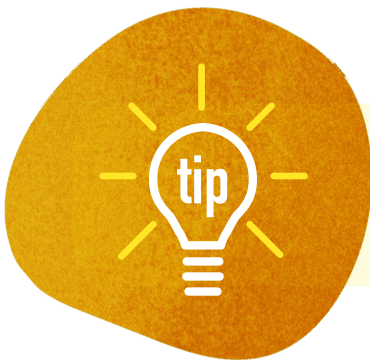
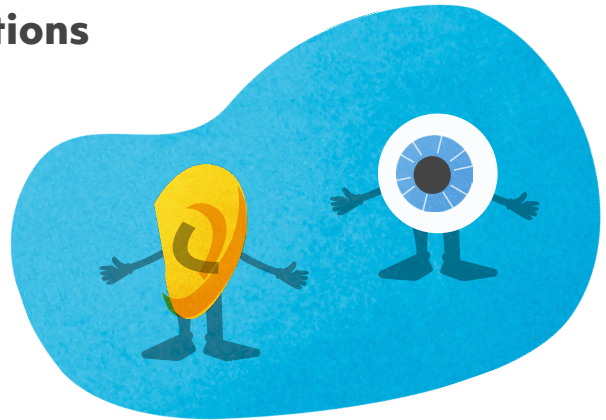
*This Infographic provides budget considerations for in-person, virtual, and hybrid events, but is not an exhaustive list of expenses.*



## Attendee Driven Budget Considerations

If you have attendees with **hearing impairments and/or vision impairments**, you might consider providing the following accessibility accommodations:

- **Support Service Providers** (SSPs) give visual and environmental information to people with visual and/or hearing impairments.
- **Communication Access Real-time Translation** (CART) services transcribe spoken text and sound into words in real-time. The words can be shown on a screen or streamed to a personal computer or device.



Budget friendly options for this include  
**Zoom Captions and YouTube Captions.**

- **Assistive listening devices**, such as FM systems or microphones, stream sound to Bluetooth hearing aids or cochlear implants.
- **Sign language services** can include platform interpreters, one-on-one pro tactile interpreters, and haptics communicators who provide environmental information in addition to signed communication. When booking these services, ensure that the interpreters are certified. To keep costs down, book interpreters well in advance of your conference.

**Be sure to ask your attendees about the services they use.** For example, if none of your attendees use ASL, then an ASL interpreter is not needed.

Finally, consider **providing captions** for all video presentations. Captioning services should include text transcripts.

# How to Raise Money for Your Conference

To cover costs, consider holding fundraising events, researching grant opportunities, and soliciting sponsorships.



For fundraising event ideas, listen to the *Once Upon a Gene* podcast on fundraising strategies for advocacy groups.

> [effieparks.com/podcast](https://effieparks.com/podcast)

## Explore funding opportunities for in-person research!

**Simons Searchlight** offers gift funding through the Simons Foundation to patient advocacy organizations hosting conferences with a significant research focus.

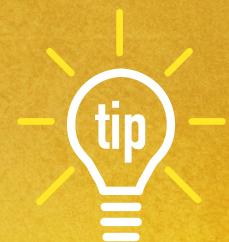
Global Genes facilitates peer-to-peer connections through its Global Advocacy Alliance (GAA), a global community dedicated to transforming the rare disease landscape. Patient advocacy groups can join GAA to access additional fundraising support and connect with other advocacy leaders.

Also consider PCORI (Patient-Centered Outcomes Research Institute) and the NIH R13 mechanism for grants that provide conference support.

Contact organizations in your advocacy area or relevant pharmaceutical companies for potential sponsorship opportunities. Creating sponsorship tiers could help you to solicit different types of sponsors and donations. >> See the *sponsorship template and sample prospectus from STXBP1* in the “Resources” section for ideas on conference support programs.

“Clearly outline the benefits included in each sponsorship tier to help sponsors assess the Return on Investment (ROI) of your event. Also, remember to ask for contributions frequently and from various sources, as many **small donations can accumulate into a significant budget.**”

— Patient Advocacy Group Member



# Select a Venue

Finding a location to host your meeting is an important step in the planning process. When selecting a location, consider whether the size of your community will influence space requirements. You should also consider the style of the sessions taking place at your event by asking yourself the following questions:

- **Will all sessions take place in one room?**
- **Will there be workshops?**
- **Will attendees be asked to move from room to room to attend different sessions?**

Answers to these questions will affect the venue you choose and the space within the venue that you'll need.

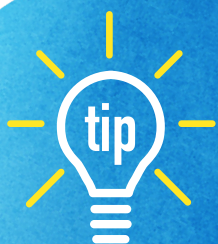
Think back to your needs assessment, and consider whether the potential venue adequately meets the needs of the patients and families who will attend your conference.

It is important to consider accessibility; accommodations; proximity to nearby amenities, such as restaurants, hotels, and childcare facilities; proximity to medical facilities; and proximity to larger conferences that families may be planning to attend, such as Global Genes events.

Select a venue with easy access from airports and train and bus stations. If the hotel provides a shuttle, ensure that the service is accessible.

To ease the financial burden on families, consider the costs for accommodations and other daily expenses. Venues that include hotels that are attached to event spaces can improve accessibility and reduce the travel costs for attendees.

You should anticipate and address concerns related to proximity to loud noises or simultaneous events at the venue during your conference. To create a comfortable and focused environment in which all attendees can fully engage with the content, strategically plan your conference schedule, include designated quiet spaces, and communicate clearly with attendees.



**"Do not forget to consider venues that have or are near **fun activities for families.**"**

*— Patient Advocacy Group Member*

# Accessibility Considerations at the Venue



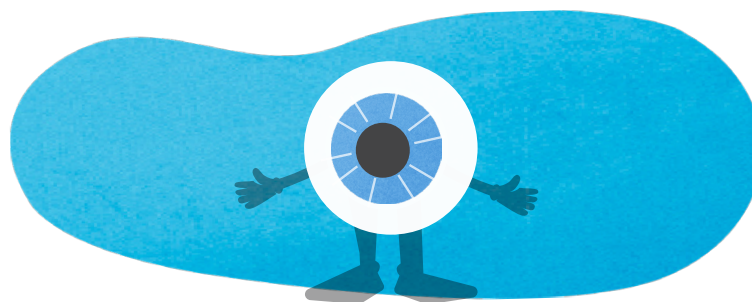
If you have attendees with **visual impairments**, be sure to discuss accommodations well in advance with hotel and venue staff. Any signage at the venue should be in large sans serif font with high contrast (ie, black on white or white on black). Recommend that the venue staff use high contrast tape to mark rooms, stages, steps, railings, and aisles. All electrical cords should be secured to avoid tripping hazards, and lighting in hallways and session rooms should be adjusted for optimal access and safety.

Because some attendees might have mobility canes, guide dogs, or other devices, ensure ample space to safely navigate around tables and chairs, and consider whether you will need to create a dog relief area.

To ease travel between conference sessions, consider the following:

- **Holding all sessions on the same floor in rooms with close proximity to one another.**
- **If session rooms are far apart, create online maps with auditory descriptions of the conference venue to ease navigation between rooms for people with visual impairments.**
- **Ensure that any windows in rooms are shaded to limit glare and improve screen readability.**

Consider training hotel staff on how to interact with guests who have visual impairments. For example, saying 'Hello, this is Mary from housekeeping. Have a nice day.' to let a blind person know that someone is passing by. Directions should be given from the perspective of the person who is visually impaired: 'Walk to your right/left'; 'It is directly behind you'; 'The restaurant is two doors down on the right.' Avoid using generic descriptors such as here, over there, or go that way. Be sure that housekeeping is aware that ribbons, markers, or other tactile cues might be affixed to a room door to ease tactile identification for a visually impaired guest.



## Accessibility Considerations at the Venue



If you have attendees with **mobility impairments**, consider the following:

- **A venue that has accessible public transportation options. This is important for those not able to drive, as local taxis might not accommodate wheelchairs or scooters.**
- **Confirm that the venue is wheelchair accessible through the main entrance.**
- **You might want to request an ADA compliance statement to ensure that the venue meets the accessibility requirements of U.S. law.**
- **Find out if there is adequate parking and whether travel from the parking lot to the venue is accessible. Ensure that ramps are ADA-compatible (eg, not too steep for safety).**

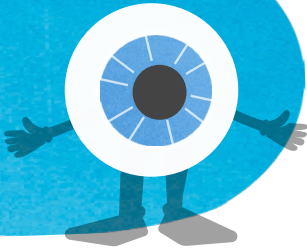
If your conference will be in a separate space from hotel accommodations, ensure that travel between potential hotels and the conference is accessible. If your conference is in a large conference center, ask if they have a golf cart or power scooter that attendees can take advantage of to get from point A to point B.

The session rooms should be large enough to accommodate wheelchairs and scooters. To accomplish this, consider using rooms that are larger than needed for the number of attendees. Also consider the proximity and accessibility of the restrooms (eg, universal changing tables).

**“Ensure easy access to power outlets for charging assistive devices during sessions. Provide convenient charging stations or power strips throughout the venue.”**  
— *Patient Advocacy Group Member*



## Accessibility Considerations at the Venue



If some of your attendees have **trouble hearing**, ask the venue if they can adjust the lighting. Soft, even lighting is best, and it is better to light the stage from the back of the room instead of shining lights directly on the speakers. Bright lights in front of speakers can make it hard to read lips or see sign language clearly, so it is best practice to avoid that setup.



Purchase **lanyards** in different colors to identify attendees with visual, mobility, and hearing impairments, but be aware that some attendees might choose not to wear a lanyard. Provide tactile markings on hotel key cards to help attendees with visual impairments successfully swipe and unlock their room door.





# Negotiate Contracts

When negotiating contracts with hotels or institutions, there are many details to keep in mind. Remember that all quotes you receive are negotiable—do not accept the first quote as final and always ask for discount or nonprofit rates or concessions.

## Venue Negotiation Strategies

For hotels, be sure to ask for room block discount rates, complimentary parking and meeting room space, catering discounts, and local attraction discounts. In addition, because hotels might have higher costs for AV services than local vendors, try to negotiate a contract that does not require Encore or other in-house AV services. This may be difficult to secure, but it is worth a try.

When considering venues, think outside the box and explore options like universities and libraries. Many universities offer summer housing or hotels managed by their hospitality programs, which can be excellent alternatives for accommodation. When collaborating with academic or hospital institutions, leverage their event planning support, as they often have negotiated hotel rates available or may assist in negotiating competitive rates. Holding your conference on an academic or hospital campus in a smaller community can also lead to significant cost savings.



If your conference includes research activities (ie, blood sample collection, in-person assessments), consult with the venue early to discuss any restrictions and required documentation, such as insurance. This is particularly important for hospital venues. Address these considerations in advance to help avoid logistical issues and ensure smooth research operations.

**>> See the “*Researcher Engagement and In-Person Research*” section on page 18 for more considerations.**

## Standard Hotel Contract Clause and Policy

**Audit clause**—Hotel will credit Group for reservations made by an attendee no matter what rate is confirmed or if room was booked outside of Group room block.

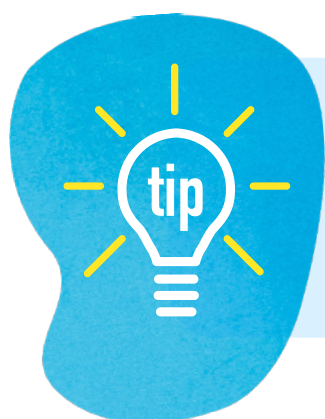
**Walk policy:** The hotel will prioritize relocating guests who are not part of this group's room block. If a guest from this group does need to be moved to another hotel, we will provide transportation, including accommodations for ADA and parking needs.



# Develop Your Program

If you conducted a needs assessment, you should have a good idea of the knowledge gaps and interests in your community. You should aim to create a balanced agenda with sessions for various interests, professional backgrounds, and age groups. For example, sessions might include panel discussions, workshops, and interactive events that cater to diverse interests and learning preferences. Ensure that the agenda is balanced between expert-led sessions and community-led discussions.

No needs assessment? No worries! Open a call for proposals, issue a short survey to gather input, or leverage your planning committee for assistance.



**“Birds of a Feather”** sessions that match attendees together based on characteristics, such as area of focus, geography, or diagnosis, can be a way to incorporate interactive elements to foster engagement and facilitate meaningful connections among attendees who share similar interests or experiences.

## Strategies for Engaging Speakers and Enhancing Attendee Experience

Consider implementing a “first time attendee” approach, including icebreakers and networking activities, to acquaint attendees with one another. In addition, allocate unscheduled time to support organic connections among families, researchers, and attendees, thereby promoting opportunities for networking and community building.

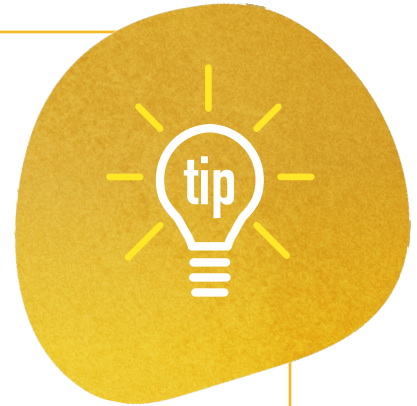
Your planning committee should have developed strategies for identifying and inviting relevant speakers. To provide a well-rounded perspective, plan to reach out to researchers, medical professionals, and community advocates. Be sure to contact prospective speakers at least 9 months to a year in advance of the anticipated conference dates to allow time for the engagement process. In addition, consider shaping the content by specifying topics you would like speakers to cover, selecting moderators for panels, and establishing agreements with speakers to ensure clarity and commitment.

Remember that speakers might have hearing or visual impairments or use mobility devices. Ensure that you account for this and make the proper accommodations.

## Develop Your Program

“If you are collaborating with Simons Searchlight or Global Genes to find speakers, please **engage these organizations as early as possible** to ensure that they can identify a speaker for your conference. Be sure to include details like agendas, topic needs, and presentation time allocation. This information may also aid in receiving potential funding.”

— Patient Advocacy Group Member



### Preparing Speakers

Set up one to two prep calls with your speakers between one and three months before your event. If you have panels, you should find a time that works for all panelists to be on the prep call together. You can use a Doodle poll or Calendly to find a time. This will give your speakers a chance to get to know each other and for the moderator to gain a sense of each speaker's area of expertise. It is also an opportunity for you to clarify any goals for the panel or topics you want discussed. You can use the prep call to remind speakers of any outstanding items they need to complete, such as signing their speaker agreement and sending in their headshot and biography.

Ask your speakers to submit two to three discussion questions that they want to be asked during the panel. The moderator can take these questions, along with other information they gathered in the prep call, to create a discussion guide for the panel.



## Develop Your Program

### Researcher Engagement and In-Person Research

Invite researchers to present their findings, interact with families, and potentially conduct short studies at the conference (pending Institutional Review Board approval). This engagement enhances discussions, promotes collaboration within your advocacy community, and advances knowledge in the field.

Ensure that there is a dedicated space to accommodate any in-person research, including assessments or blood sample collection. Set up a sign-up process for attendees interested in participating. Promote the research opportunities to attendees directly—do not rely solely on researchers to coordinate attendee involvement in any research activities.

Considerations for securing rooms for **research activities**:

- **Ensure privacy, confidentiality, and accessibility for all participants.**
- **Maintain medical hygiene standards, proper waste disposal, and emergency protocols.**
- **Confirm space and facilities for equipment, and coordinate with venue staff and medical professionals in advance.**
- **Plan schedules to avoid overcrowding and clearly communicate details to participants.**
- **Ensure legal, ethical, and regulatory compliance.**

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### Real-time Captioning

You might want to think about hiring someone to provide live captions for your sessions. Make sure to plan for this in your budget, as it can be costly. Finding a skilled captioner can also be tricky—it is important to check their qualifications and make sure they understand the medical terminology used in your field. Alternatively, you could consider using AI captioning services, such as Wordly. These services can help make your conference accessible to everyone by automatically generating captions in real-time. >> *See the “Create a Budget” section on page 7 for other considerations.*

Captions can be set up on a separate screen near the main screen. Be sure to include all important announcements in the captioning.

## Develop Your Program

### Making Your Conference Family Friendly

- Provide a **family hospitality room** where parents can watch live-streamed sessions and stay involved in the conference. The hospitality room could replace a childcare room if it is too expensive to provide one.
- If siblings are attending your conference, **provide a sibling space** to make them feel extra special.
- **Include social events** to foster connections among families or between families and researchers.
- Provide separate **break-out sessions** for moms, dads, and siblings to allow opportunities for like-minded individuals to connect.

To foster inclusivity, consider incorporating hybrid elements. Attendee engagement through hybrid events can help to create a robust online presence and sustain an active virtual community. Use live streams for key sessions, interactive online forums, and virtual networking events to enhance participation for those unable to attend in person. Leverage technology to enable seamless interaction between on-site and remote attendees. You can also provide session recordings for later access, ensuring that your conference lives on after completion.



Conference speakers should be aware when there are attendees with visual impairments. Be sure to advise your speakers on the use of presentations that are accessible for people with visual impairments. For example, speakers should choose Arial fonts and bold white fonts on dark backgrounds. They should also know how to describe the images on their slides to make them more accessible.

# Cover All the Logistics

## Conference Registration

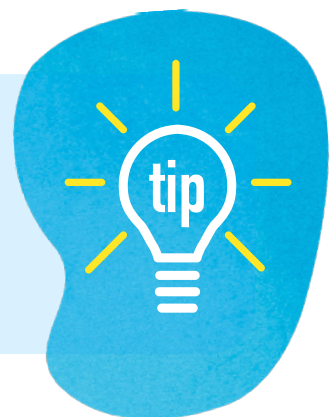
To facilitate the registration process, provide a step-by-step guide for attendees to register online. The registration platform should be user-friendly, and you should clearly communicate the registration process to members of your community.

In addition to early-bird discounts, consider offering scholarships or reduced fees for people facing financial hardships. It is important to be transparent about the costs of attending your conference and what is not covered in the registration fee (eg, hotel accommodations, airfare, ground transportation, meals that are not covered).



Before launching your registration platform, you should perform tests with different screen readers to ensure accessibility to people with visual impairments. If possible, reach out to appropriate advocacy groups, such as the American Foundation for the Blind or the Foundation Fighting Blindness, for guidance on accessible event and registration apps.

**The Web Accessibility Initiative** provides guidance on how to make websites or online resources fully accessible. Consider referencing this resource to ensure individuals with disabilities are able to navigate and interact fully with your content.



Once you have a registration platform, create a thorough description of the registration process for people with visual impairments. To ease registration, ensure a simple online process.

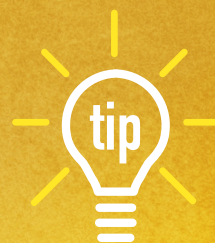
## Cover All the Logistics

### Hotel Accommodations

Your registration process should include information on recommended hotels and any discounted room blocks, as well as instructions on how to book these accommodations. Also, provide information on accessible accommodations for attendees with specific needs and ensure that hotel rooms are equipped with refrigerators to accommodate the unique needs of families.

**“Do not be afraid to **negotiate with hotels** for a room block at different price points to accommodate various attendee budgets.”**

*— Patient Advocacy Group Member*



### Meal Planning

When planning meals for your conference, talk with the caterer to create inclusive menus. If attendees require special meals, consider issuing tickets they can present to the waitstaff for their needs. Buffet-style meals can enhance accessibility and coordination compared with plated meals. Alongside the main buffet, consider offering a separate buffet for children. It is also important to account for common allergies and have a strategy in place to accommodate attendees with dietary restrictions.



Plan to have someone who can provide verbal descriptions of buffet items. For plated meals, high contrast between table linens and dishes is preferable (eg, black table cloth with white dishes). Consider food selections that are easy to manage on a plate. For example, avoid ribs, meat with bones, and large portions of meat or vegetables that are not pre-sliced.

Choose easy-to-cut meats, portion-sized proteins and vegetables, and single-serve desserts. Servers should use verbal cues when approaching and clearing dishes and utensils: ‘This is your waiter coming in on your right to clear your place setting.’

## Cover All the Logistics

### Childcare Accommodations

Because childcare expenses can pose a challenge for attendees, consider cost-effective alternatives to alleviate this potential barrier. Note, there could be additional insurance requirements associated with childcare accommodations, so don't forget to add this into your budget!

- **Consider partnerships** with local institutions or community groups for childcare services during the conference.
- Communicate the level of childcare provided and **set clear expectations** for caregivers and attendees.
- **Offer different care options** based on age groups and specific needs to maximize attendee participation.
- **Provide a list of local childcare** resources for attendees to arrange their own services, ensuring flexibility.

### Caregiver Accommodations

In order to attend a conference, many caregivers may have to hire a caregiver or bring their family member with them. Consider cost-effective alternatives to allow caregivers the opportunity to fully participate in the conference.

- Explore **partnerships with local institutions** or caregiving services.
- Consider partnerships with **local caregiving services** to provide assistance.
- **Communicate the level of caregiving** provided for pediatric, young adult, and adult patients.
- **Set clear expectations** for caregivers and attendees regarding the level of care.
- **Provide additional accommodations**, such as private changing rooms or feeding areas for caregivers and patients of all ages.

## Cover All the Logistics

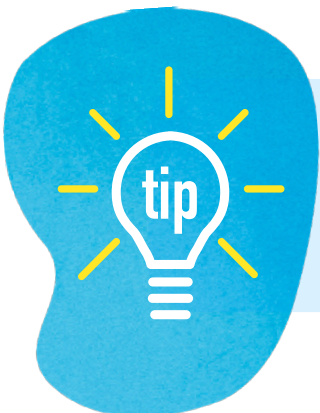
### Address Language Barriers

To ensure accessibility to as many attendees as possible, address any potential language barriers that might exist. You can share presentation slides with attendees ahead of time or provide slides on a personal device during the sessions. This can also be helpful for attendees with visual or hearing impairments. Research potential useful technologies, such as SyncWords for translation of presentations. You might also consider asking members of your community for volunteer help with translating captions or transcripts post-conference.

### Anticipate Attendee Questions

Create an internal Frequently Asked Questions (FAQ) document to help you manage attendee questions during the conference. Also plan to have dedicated staff or volunteers to help attendees on-site. Communication channels, including print, signs and web, should be accessible with information that is up-to-date for internal and external visibility. Be sure to brief your internal team pre-conference to ensure that everyone is on the same page.

» See the “[Resources](#)” section for FAQ templates.



If you are not local to the venue, **consider assigning a host family or volunteer** to collect shipments, recommend local services and vendors, and **help recruit local volunteers**.





# Create Your Marketing, Communication, and Promotion Strategy

Once you finalize the budget, theme, audience, and goals for your conference, the next step is to develop a comprehensive marketing plan that will help you promote the event. This plan might include social media promotion, email campaigns, partner outreach, and traditional advertising.

» See the “[Resources](#)” section for many sample marketing templates that can help support your outreach efforts.



**“Ask community members** to donate time for creating marketing materials and leverage established partnerships with organizations for cross-promotion.”

— Patient Advocacy Group

**Here are a few materials you might want to develop for marketing your conference.**

## Social Media Graphics

Images can be used by your internal team to promote your conference on your social media platforms. You can also develop graphics for volunteers or your organization partners/friends to share and help bring awareness of your event to their communities. Shareable graphics for registrants are also a great way to build excitement and allow community members to promote the conference on their social media. Incorporate visuals that showcase keynote speakers, session highlights, and exciting conference features to drum up excitement beyond the standard image reminder.



## Create Your Marketing, Communication, and Promotion Strategy



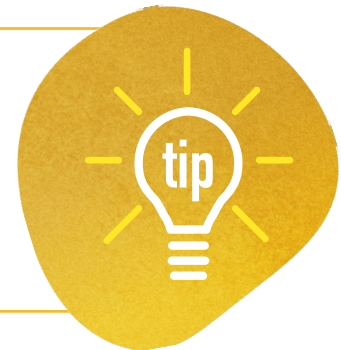
Leading up to your conference, you could **create save-the-date email campaigns** featuring countdowns, or engaging conference-related content for use across email and social media platforms.

### Marketing Toolkit

A toolkit is a great resource that your staff and volunteers can reference when promoting the conference. It is also helpful when asking external parties to share your event.

- The marketing toolkit should offer details about the conference, such as location, date, and registration link. It should also include contact information for inquiries regarding sponsorships, marketing, customer service, and more. In addition, the toolkit should provide promotional images and text suitable for sharing on social media or in email communications.

**Canva** is a great graphic creation tool that provides discounts to non-profit organizations. Use Canva to create a wide range of visuals, including social media graphics, flyers, email templates, posters, and more. The vast collection of templates makes designing your images a seamless and creative process.



### Email Templates

Email marketing is an impactful way to relay event details to your audience. These emails serve various purposes, from initial conference announcements and open registration notifications to event reminders, exciting event updates (such as early-bird pricing and keynote speakers), 'Know Before You Go' guides for attendees, and post-conference surveys or updates.

- The content of each email template will differ depending on the purpose of your communication. For conference-related emails, it is essential to include all relevant conference details like event name, conference dates, conference location, registration link, registration deadline, conference schedule, any sponsor recognition, and a clear call-to-action.

## Create Your Marketing, Communication, and Promotion Strategy

### Email Templates (cont)

Types of emails you might send include:

- **Conference Announcement:** This will typically be your first touch base about the conference with your email list. An email announcement should not be sent until you have your registration link available for use as a call to action. Key features to include in this email, aside from the necessary event information, are highlights about your event that will appeal to your audience and speakers
- **Conference Reminders:** This includes reminders about the conference to drive more registration. Key features to include are new highlights that haven't been included in previous email announcements or reminders like announcing new speakers or sessions. Conference reminders can also include communication to attendees only to remind them to sign up for any additional features within your conference, to book their hotel room, or present a poster.
- **Know Before You Go:** This email is intended for registered attendees, providing essential details about the conference, such as registration dates, times, and venue location; conference hotel amenities, including Wi-Fi, accommodation information, any health advisories, and meal details; the conference schedule; attire guidelines; and other important preconference information to enhance attendees' overall experience.
- **Post-Conference Emails:** Sending your attendees a thank you after the conference is a great way to stay connected and show your gratitude. It is also a great touch point to share additional post-conference information like:
  - Post-conference survey to receive feedback
  - If you hired a photographer, it would be a great way to share photos with your attendees
  - If your attendees consented to sharing their contact information with other attendees, you can share a list so that connections can continue after your conference ends



**Please keep in mind that your email schedule and strategy should be customized to fit the size and capabilities of your team.**



## Create Your Marketing, Communication, and Promotion Strategy



Use services like Mailchimp or event management platforms like Hopin or Cvent to create email templates, and include clear instructions on how attendees can reach out for support or additional information.

### Here are other marketing and communication strategies to consider.

- Establish a dedicated **online forum or Facebook community group** for ongoing communication. You can host virtual town hall meetings or webinars to address questions and concerns before the conference.
- **Seek help from your network!** Are there other organizations that might be interested in promoting your conference to their audiences? Connect with them to see if it is possible to share your event on their social platforms or email communications.
- Create **conference flyers** that can be distributed by volunteers, internal staff, or organization partners.
- **Promote your conference** on podcasts, through word of mouth, at speaking engagements, at conferences, or on event hubs like the Global Genes [Community Events](#) page.
- Do some **local research**. Beyond your network, explore potential partnerships with local businesses or organizations that align with the vision of your conference.
- **If you plan to hire a photographer or videographer**, be sure to communicate this with registrants and provide a media release form for their consent. We suggest incorporating a checkbox on your registration form for agreement, ensuring consent is obtained upfront.



**Your marketing materials should be accessible for screen readers**, so be sure to use simple graphics and include alternative (Alt) text for any images or photos. If you use hashtags in communications, capitalize each word in a phrase so they can be read properly by screen readers: #RareDisease instead of #raredisease.



## Section

# 2 On-site Operations

When onsite, it is important to have your documents for each day organized into folders, either on your desktop or in a shared drive. In each folder, you should have all presentation (i.e. PowerPoint, keynote, PDF, etc.) files that need to be shared during the sessions of that day, as well as any staffing documents or facilitator instructions. You might consider including a “rotating slides” PowerPoint deck to show during breaks that includes information about certain programs you want to highlight, the Wi-Fi password, and links to a post-evaluation survey. Remember to keep these slides short, as they will flip from one slide to the next fairly quickly during the break times in your agenda. You can also include a deck with title or transition slides. These will outline the title of each session and the speakers for that session to be displayed once the session starts.

To ensure a smooth event, it is helpful to have a **run-of-show Excel sheet**, and a staffing document. The run-of-show sheet is especially important if you are working with an AV team. It will provide the AV team with all the information needed to transition from one speaker or panel to the next, including the name and time of each session, the name and contact information for each speaker, and if there are any slides being used. Note, it is important that the run-of-show sheet reflects the title of each PowerPoint word for word.

➤➤ See “**Resources**” for sample registration questions, an AV run of show and Event FAQ template.

The staffing document should outline the responsibilities of your staff/volunteers throughout the event. It tells your staff/volunteers what sessions they are supposed to attend and in what capacity (eg, door greeter, mic runner, facilitator). A facilitator opens the session by introducing speakers and closes the session by telling attendees what is happening next on the agenda. It is helpful to hold a training with staff/volunteers ahead of the conference to review their responsibilities. It can also be useful to create guides for each of the duties performed as a reference document for your staff. ➤➤ See the “**Resources**” section for a day of staffing document template.

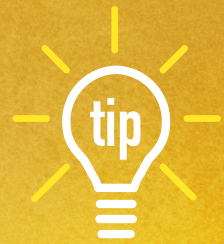
The program manager or individual responsible for driving the agenda should **sit at the AV table to help troubleshoot** if problems arise. They know the content best and will be the best suited to help make adjustments on-site as needed.



## Emcee

It can be helpful to have a single person act as the emcee for the entire conference. This can be a staff member or an external volunteer. They will act as a conductor of sorts to transition between sessions by providing background information on the session that is about to take place, introducing speakers, and helping remind attendees of logistics such as filling out a post-event survey. They will act as timekeeper and can signal to a session moderator when it is time to wrap up and move to Q&A. This person is also useful to vamp (ie, talk to the audience to take up time while the AV team is getting the next session set up or if a logistical problem arises). Having an emcee can help keep your conference on time and moving smoothly.

Make sure to **budget time for Q&A** when you are prepping speakers. It is important to give your attendees a chance to engage with the content in an active discussion. However, don't be afraid to cut things off. You need to keep the day moving, and there will always be more questions. If all questions are not answered during the allotted time, suggest that attendees find speakers during breaks or meal times to continue the conversation.



## Volunteers

If you will use volunteers during your conference, it is important to develop guidelines for volunteer recruitment and management. To help coordinate your volunteers, create specific roles for tasks that need to be completed, such as assisting with registration, moderating sessions, or guiding attendees. Plan to provide training sessions for volunteers, including a Pre-conference orientation, and be sure to acknowledge their contributions. Consider recording these trainings for any volunteers unable to attend the live session. >> See the **"Resources"** section for volunteer tasks.

## Emergency Response Plan

It is prudent to have an emergency plan that includes who should be contacted and what procedures should be followed. For example, your plan should provide the contact information for on-site medical support and clearly communicate the emergency exit routes.

The hotel or venue space should be your partner in this effort, so be sure to collaborate with the appropriate staff when developing an emergency response plan. Consider holding joint training sessions to ensure safety and efficiency during unforeseen events.

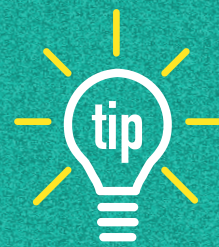


## Point Persons

It might be helpful to have multiple event point persons who can manage logistics and operations during your conference and ensure that everything runs smoothly. They should cover tasks such as in-person technical support, online technical support for hybrid events, and directing attendees to the appropriate resources.

**“Do not expect perfection — **enjoy the conference and take it all in** once things kick off!”**

*— Patient Advocacy Group*



Fully sighted volunteers and hotel staff should be aware when there are attendees with visual impairments. This is particularly important during emergencies, as these attendees might have additional challenges evacuating the venue.

During Q&A sessions after presentations, it can be helpful to have mic runners for attendees who are visually impaired so that they do not have to navigate to a standing microphone. Also plan to have volunteers who can provide directional assistance between sessions, as well as food service assistance at buffets.

If an event planner is blind or has a visual impairment, they can team up with a sighted assistant.



In session rooms, consider blocking off sections at the front so that people with hearing impairments can more easily read lips and view captions or sign language.



## Section

# 3 Post-conference Activities

### Evaluation and Feedback

When your conference wraps up, the work is not done. You will want to evaluate your conference's success through attendee feedback.

You should create feedback surveys for attendees to provide their opinions on the sessions, the conference logistics, and their overall experience. Be sure to include questions on the relevance of each session, the effectiveness of the speakers, and any suggestions they might have for improvements. It is helpful to have a mix of quantitative and qualitative questions to aid in evaluating your success and for planning future conferences. >> See the [“Resources”](#) section for *post-conference survey templates*.

**“Remember to handle any funding reconciliation that is required from funders.”**

— *Patient Advocacy Group*



You should plan to conduct a post-conference evaluation to assess overall success. Consider in advance what markers would indicate success for your conference to help guide your evaluations and future planning. Example measures might include attendance numbers, social media engagement, and specific attendee feedback. Consider conducting post-conference interviews or focus groups for more in-depth insights.

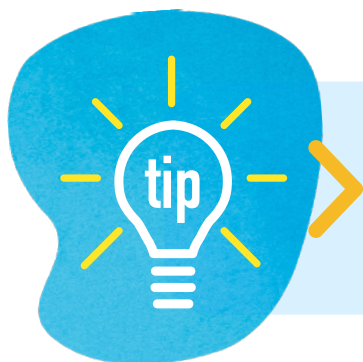


To ensure participation in post-conference evaluations, feedback surveys should be accessible for screen readers and screen magnification programs.



## Archival Resources

You should consider creating an online repository of conference materials that attendees can access post-conference. This could include links to the presentations, videos, and additional resources. Explore partnerships with platforms that specialize in archiving medical and advocacy content.



### Use YouTube to host your panel recordings for free!

It's an affordable solution that offers accessibility features like subtitles, making it perfect for international audiences.

## Thank You Materials

It is helpful to create templates for post-conference thank you notes. Plan to send personalized notes to sponsors, speakers, and attendees, expressing gratitude for their contributions.

## Community Engagement

You will want to follow up with community members to sustain engagement after your conference. You can continue discussions on your community's online forum, share post-conference resources, and initiate new community projects. Encourage community members to interact by sharing their conference takeaways and experiences. Use email blasts, online happy hours, and webinars to keep attendees connected to the research opportunities that they might have participated in at the conference.

To foster continued engagement, encourage attendees to set personal action items based on what they learned at the conference. You can create a social media template for attendees to share their action items inspired by the conference, and host follow-up activities (eg, webinars) to support the implementation of action items.

Researchers can also help with community engagement. Encourage them to share back their learnings from the conference with community members through live or virtual events.

You might also consider establishing a year-round planning committee that can maintain ongoing communication, share updates, and address emerging community needs.

## Planning for Future Conferences

Use the momentum of conference completion to conduct a debrief with your team to gather key insights. Solicit team feedback on successes, challenges, and areas for improvement. Based on team feedback, create an action plan for future conferences. Your year-round planning committee can evaluate feedback and implement changes for future conferences.

# Conclusion

## Congratulations on reaching the end of this toolkit!

You now have a powerful resource at your fingertips for planning impactful patient and research conferences. Armed with practical tools and insights, you are well-equipped to navigate the nuances of event planning and strengthen connections within your community.

Always remember, your event is more than just a logistical endeavor—it's a chance to ignite change and propel our shared mission forward. Trust your instincts and create events that leave a lasting imprint on rare disease advocacy. You are doing your best, and that is something to be proud of.

**Here's to the incredible journey ahead!**



## Resources

How To Design An Accessible Event For The D/deaf And Hard Of Hearing

[dc.aiga.org/how-to-design-an-accessible-event-for-the-d-deaf-and-hard-of-hearing](https://dc.aiga.org/how-to-design-an-accessible-event-for-the-d-deaf-and-hard-of-hearing)

Accessible Conference Guide

[sigaccess.org/welcome-to-sigaccess/resources/accessible-conference-guide/#planning](https://sigaccess.org/welcome-to-sigaccess/resources/accessible-conference-guide/#planning)

### TEMPLATE EXAMPLES

Find all the templates below at: [bit.ly/PAG\\_Toolkit\\_Resources\\_Templates](https://bit.ly/PAG_Toolkit_Resources_Templates)

- AV Run of Show
- Conference Announcement Image
- Conference Announcements
- Conference Session Image
- Day of Event Staffing
- Event Budget
- Event FAQ
- Events Run of Show
- Image That Can Be Shared by Attendees
- Marketing Toolkit
- Post-Conference Feedback Survey
- Registration Questions
- Reminders—Registration Deadlines, Conference Schedule
- Sample Post-Event Survey Questions
- Social Media Templates
- Speaker Announcement Image
- Sponsorship Letter
- STXBP1 Summit+ 2024 Sponsorship Prospectus Letter

## Acknowledgments

### Effie Parks, *Once Upon a Gene* Podcast

EPISODE 201 - Five Advocacy Aces Share Their Conference Commandments:

[effieparks.com/podcast/episode-201-rerelease-five-advocacy-aces-share-their-conference-commandments-szglr](http://effieparks.com/podcast/episode-201-rerelease-five-advocacy-aces-share-their-conference-commandments-szglr)

### To all the patient advocacy communities that responded to our survey:

Alliance of PKU Families	Global Pediatric MDS Initiative	Perthes Kids Foundation
Angelman Syndrome Foundation	GRIN Europe	Raising Hope International Friends
ASXL Rare Research Endowment Foundation	Helping Hands for GAND	SATB2 Gene Foundation
CACNA1A Foundation	HNRNP family foundation	Setd5
Canadian Association for Porphyria	International FOXP1 Foundation	SHINE Syndrome Foundation
Canadian Association of Pompe	International FOXP1 Foundation	Siegel Rare Neuroimmune Association
Care4ASH1L	Jansen de Vries Syndrome Foundation	TANGO2 Research Foundation
CHARGE Syndrome Foundation	KIF1A.ORG	Tatton Brown Rahman Syndrome (TBRS) Community
Child and Youth Care	Koolen-de Vries Syndrome Foundation	The MANDKind Foundation
Coffin-Siris Syndrome Foundation	Krishnan Family Foundation	TRIP12 Gene Community
CSNK2B Foundation	MED13L Foundation	US MEF2C Foundation
CTNNB1 Connect And Cure	Mississippi Metabolics Foundation	Usher Syndrome Coalition
DDX3X Foundation	MitoAction	White Sutton Syndrome
Duplication Cares	Myrovlytis Trust	
DYNC1H1 Association	New Zealand Pompe Network	
Fabry Support & Information Group	NRXN1 Network	
Familial Dysautonomia Foundation	PACS2 Research Foundation	
FD/MAS Alliance	Pediatric Epilepsy Surgery Alliance	