



Conference Planning Guide

Table of Contents

<u>Conference Planning Guide</u>	<u>Page</u>
1. Introduction	2
2. The Role of the Board and the Conference Planning Committee	2
3. Conference Title	3
4. Selecting a Date	3
5. Selecting a Venue	3
6. Creating an Agenda	5
7. Budget and Finances	6
8. Raising Funds	7
9. Group Communications and Advertising	7
10. Registration	8
11. Child Care	8
12. Volunteers	9
13. Special Touches	9
14. Evaluation and Follow-up	10
15. Conference Planning Deadlines	10
16. Sample Project Task List	11
17. Presenter Request form	14

1. Introduction

Each year 1p36 Deletion Support & Awareness organizes a family get-together and conference. This is ordinarily a three day gathering with members of the group and experts in fields that are pertinent to group member's needs. Each year a different location is chosen to host this conference and an individual or couple from the group, assisted by a committee of helpers, takes responsibility for organizing and carrying out the conference in that location. This guide is intended to be a resource for those conference planners and is not an attempt to dictate content to the extent of replicating past conferences. This guide is to serve as a planning tool assisting conference committees so as not to "re-invent the wheel." It should help expedite and guide the planning process.

The conference should provide programs of varying formats, ranging from speakers, panel presentations, workshops, audio visual presentations and social events, and reach out to all types of members. 1p36 Deletion Support & Awareness conferences have evolved somewhat over the years but there is one important element of the conference that the board feels very strongly about preserving. It is the caring, nurturing family atmosphere that brings the 1p36 community together and makes our conferences so special. We must be careful to protect this element and allow for time where families can connect with one another and support one another. No matter how large our organization may become we must never lose sight of the need to include and plan for the nurturing and healing that needs to take place when we all come together.

Planning a 1p36 DSA Conference involves a great deal of effort, but it is also very rewarding. The annual conferences provide a rare and exciting opportunity to meet other families who are dealing with similar challenges and working to overcome them. On behalf of the 1p36 Deletion Support & Awareness, thank you for being willing to take on this important role.

2. The Role of the Board and the Conference Planning Committee

Each year a Conference Planning Committee is tasked with the responsibility to carry out a successful event. One individual acts as the chairperson of the conference planning committee. This individual ordinarily lives in or near the host city for the conference that year. The 1p36 DSA board is responsible for determining who the conference planning committee chairperson is and what city the conference will be held in. The host city and chairperson will be chosen no later than 2 years before the conference.

The Conference Committee Chairperson is responsible for coordinating conference planning activities with the 1p36 DSA Board through the Vice President of Membership (Internal). The Vice President of Membership (Internal) will be the chairperson's primary resource when questions arise or help from the

board is needed. This person should be kept in close contact during venue and date selection, budget planning and so on. The Treasurer is the board member who handles financial details such as expense requests, reimbursement checks and the budget. More information about this topic will be covered in the Budget and Finance Section of this guide. The chairperson may be asked on occasion to attend 1p36 DSA board meeting calls to coordinate planning efforts.

The chairperson is responsible to select the other members of the conference planning committee. There is a minimum requirement of 3 conference planning committee members. This number includes the chairperson. It is strongly advised that the conference committee chair have sufficient committee members to delegate the many responsibilities of conference planning and while a minimum of 3 conference planning committee members is required it is suggested to have 4 or 5 committee members. Conference Planning Committee members do not have to live in or near the host city. There will be enough to do that remote helpers can assist as well.

3. Conference Title

The title of the conference will be “The x (number of years) Annual 1p36 Deletion Support & Awareness Conference”. Any deviation from this title must receive board approval prior to the printing and dissemination of any promotional materials.

4. Selecting a Date

In order to ensure the highest possible attendance, most conferences have been scheduled in late July to Early August. This allows families with children in school, even those in unique year-round school situations, to attend without having their children miss class. Most often the conference has been held starting on a Thursday evening and finishing on a Sunday morning.

When a potential conference date is selected by the conference committee, the VP of Membership should be notified in order to get board approval. The conference committee chairperson is encouraged to discuss several possible dates in order to find one that will work best for all involved.

5. Selecting a Venue

Selecting a suitable venue to accommodate the visiting families is a critical step in planning a successful conference. Consideration should be taken for the needs of families who may need refrigerators, microwaves and cribs in their rooms. It is very important that all areas of the venue be easily accessible by wheelchair or stroller. It is also important that the staff at the proposed venue be aware of the special needs of some of the attendees and be willing to go out of their way to make the conference go as smoothly as possible.

The conference venue should have adequate rooms for the attendees and meeting space for speakers, breakout sessions and child care. There also needs to be plenty of room in the meeting spaces for families to feel free to have their kids with them and be able to spread out on the floor if necessary. The venue should have adequate catering and food services available. Location should be in close proximity to entertainment, shopping, restaurants, and recreation if possible. The venue should also have experience in hosting a family type conference such as ours. The cost of reservations has traditionally been between \$100 and \$130 a night (before tax) for attendees' rooms. Staying in this price range allows for some amenities without being too costly for most conference goers. This cost is usually kept separate from conference registration and is paid directly to the hotel without any involvement from 1p36 DSA.

We recommend visiting at least 3 or 4 venues/hotels for a tour and discussion of the above criteria. Developing a check list for comparison of pros and cons will be helpful in making a recommendation to the board. Don't be afraid to ask tough questions and introduce them to our organization. Ideally, the conference should be hosted at a medium size hotel or venue where we will be the "main act" so to speak, during the days of our conference. We don't want to be competing with other large groups for space or service.

In the end, comparing hotels is somewhat an apples to oranges game, with no two hotels or venues having the same features. After narrowing the choice to two or three, it is time to negotiate. Things like free meeting space or audio visual equipment can be standard perks. Ask for breakfasts or refreshments to be thrown in. Don't be afraid to play one hotel against another or walk away from an unfair offer. Finally, ask for references of other family type conferences. Interview the head of key service departments to get an idea of the type and degree of friendly and courteous service that we should expect. Once the final bids have been gathered, they should be presented to the board for a final decision.

When a venue has been selected, the president of the 1p36 DSA board will sign the contract with the hotel and the Treasurer will pay any necessary deposit in order to make the reservation. Bids should be submitted to the board no later than the end of June the year before the conference. The work of visiting hotels and collecting bids should begin no later than January the year before in order to have the best selection of venues.

Occasionally, conference locations that are not hotels have been considered. These can be a fun change of pace and the planning committee may discuss them as options along with more traditional locations. For example, the 2011 conference in St. Paul, Minnesota was held on the campus of Bethel University.

6. Creating an Agenda

Agendas for conferences over the years have varied a great deal. Ideally, items on the agenda should not be packed too tightly. 1p36 individuals and their families will need down time and free time in order to spend time with other attendees. Often, speakers and panels of specialists are scheduled in the mornings with activities or unscheduled time in the afternoons and evenings.

Speakers who are in the area are invited and often end up being some of the doctors and therapists who see 1p36 patients related to conference planners. This gives some variety and new perspectives. Dr. Lisa Shaffer, a prominent 1p36 Deletion researcher, has volunteered her time to attend and speak most years. The board can assist in contacting her and arranging for her participation. Other prominent speakers have occasionally been invited and can be discussed. However, appearance fees and reimbursement for speaker travel is limited and must be approved by the 1p36 DSA board.

Once the committee has a confirmation from a speaker or presenter it is advised that you send them a thank you and confirmation letter with the time and date that they are to speak. If the exact date and time are not known at that time, please let them know the specific date and time as soon as the information is available. Depending on the speaker, it is nice to make sure there is adequate Q&A time scheduled. This allows for questions to be asked and the entire group be able to hear and learn from the answer rather than each family asking similar questions after the talk is over. Each presenter should also be sent a presenter request form so that all needed equipment is available for each speaker. (see section 17)

Activities not included in the conference fee should be at no cost or low cost in order to prevent alienating attendees because they can't afford to participate. Successful activities from years past include a movie night, a nighttime dance party, pool party at the hotel pool, outdoor games, children's museum (discounted rates were negotiated in advance for the group) and visiting nearby tourist attractions.

Traditionally, there have been activities for 1p36 moms and 1p36 dads separately at some point during the conference such as mom's night out or dad's night out etc... This isn't required, but gives the men and women caregivers a chance to discuss their unique responsibilities and perspectives.

One very popular agenda item at past conferences has been a family introduction time. This can be Thursday evening or Friday morning before the first speakers. It is a wonderful time for families to introduce themselves, share some of their ups and downs and also share what they hope to get out of the conference. This get to know you time is a nice "ice breaker" and works to open up conversation between the families throughout the rest of the conference.

To see agendas from previous conference, please contact the board. The schedule needs to be approved by the 1p36 DSA board before it is shared publicly. A rough schedule should be presented to the board by the end of December in the year before the conference is held if not sooner.

7. Budget and Finances

Great care should be taken to make sure conference expenses are properly tracked and approved. A suggested conference budget will be provided by the 1p36 DSA Treasurer and reviewed with the Conference Committee Chairperson in March the year before the conference. It will be the responsibility of the Conference Committee Chairperson working with the conference planning committee to create an actual budget for the conference and review the budget with the 1p36 DSA Treasurer at least 4 months prior to the conference. The actual budget will need to be approved by the 1p36 DSA board 3 months prior to the conference. It is very important that the conference expenses be kept within the approved budget to make sure other efforts by 1p36 DSA are not impacted. The conference committee chairperson holds the responsibility to keep expenses in check. One way to reduce costs for the conference is to ask for donations of goods and services and if donations are not available to try to get discounts for items. 1p36 Deletion Support & Awareness is a recognized 501(c)3 non profit and the board is willing to help if necessary to facilitate acquiring reduced rates.

Large expenditures such as the cost of conference rooms, AV equipment and catering on the hotel bill should be coordinated with the 1p36 DSA Treasurer. The Treasurer will pay these costs directly so conference planning committee members do not have to wait for reimbursement.

Smaller expenditures such as attendee gift bags and speaker thank you gifts should be purchased by committee members. Then receipt for the items should be submitted to the treasurer with the necessary reimbursement request form. Please let the board know as soon as possible if this is not financially possible.

The following is a list of items that should be included in the conference budget:

- Hotel Conference room(s)
- Audiovisual equipment
- Catering for attendees
- Attendee Gift Bag Items
- Speaker Appearance Fees
- Speaker Thank You Gifts
- Name Tags
- Printed Agendas and Other Handouts
- Special Events
- Snacks
- necessary items for child care room

8. Raising Funds

In the year leading up to the conference, the planning committee should help facilitate fund raising to cover conference costs. It is encouraged that specific conference fundraising activities, along with registration fees, cover the entire cost of the conference. This allows other 1p36 DSA funds to be used toward other goals in the mission statement.

The conference planning committee is NOT responsible for carrying out all of these fundraisers but they should help group members to raise funds in their areas in order to cover the cost of the conference. A fundraising guide listed on the 1p36 DSA website is available to assist group members in their efforts.

9. Group Communications and Advertising

Communication about the conference should begin at the previous year's conference. This allows group members to begin planning time and saving money for the trip. The host city and conference dates should ideally be announced.

All communications on the conference should be coordinated through the Vice President of Membership. Details of the conference will be shared with the group via www.1p36dsa.org, newsletters, the 1p36 Deletion social network groups and other channels. However, it's encouraged that most publicity be linked back to the www.1p36dsa.org website where all of the details can be collected.

It's also important to hold back on information that isn't yet finalized to prevent confusion among potential attendees. If an individual is asking about the hotel and one hasn't been selected yet, it's okay to say that the information will be coming soon. Once details on an aspect of the conference have been established, sharing them as soon as possible will help to keep the excitement levels high and will improve attendance at the conference.

Communications about the conference are also a great place to solicit donations and help with fundraising. When people are excited about the conference they'll be more willing to hold fundraisers and tell their friends.

10. Registration

It is critical for conference planners to maintain a list of who will be attending and how many will be in each party. This is why registration is required for all conference attendees. Registration will be conducted electronically through a special registration page set up for the conference. The page allows the attendees to enter information about how many will be coming and to pay a small fee in order to get a firm commitment to attend. The exact contents of the page and the amount of the fee should be coordinated with the 1p36 DSA board.

The registration for the conference is usually kept separate from hotel reservations, which conference attendees are responsible for making on their own. The only time this is different is in the case of a conference held at a college campus or other unique location. Whether the registration includes lodging reservations or not should be made clear on the registration page.

11. Child Care

Child care can be an important and essential element in a smooth running and successful conference. Knowing that 1p36 Deletion Support & Awareness Conferences are often family vacations, you can expect to have many children staying at the hotel. The need for child care during the different speakers, panel discussions and other sessions of the conference is great. We strongly suggest having a registered nurse or someone with some medical background on staff at all times during child care hours. You may consider staffing the child care room with people who are comfortable working with special needs kids to allow mom and dad to “go out” yet feel comfortable leaving their children in good hands.

It is important to communicate to the hotel staff (even before a contract is signed) that this will be a family conference with many children attending. Also the staff should be aware of the fact that we will have a child care facility on site during the conference. The child care room should be large enough to section off and have a separate sleeping area, play area, changing area and have bathrooms close by. Ideally this room should be on the same floor and near the main conference room. We strongly recommend consulting with a day care operator for guidance in setting up the child care room and stocking it with supplies. Assistance with a check-in/check-out system and staffing with competent workers is essential. It is important that parents attending conference workshops and activities not only have the option of child care, but that they feel confident and comfortable with leaving their child in the child care room. The schedule of child care hours should be listed in the conference packet and posted outside the child care room. It is common for the child care room to be closed during mealtime. In addition, a cleaning schedule of the room should be agreed on with the staff.

12. Volunteers

Prior to and during the conference itself, there will be many tasks needing volunteer assistance. Depending on the conference committee alone to accomplish all the work is not at all realistic. Running a successful conference depends on many helping hands that can be relatives and or friends of committee members along with service clubs and local church youth groups.

Several months prior to the conference, a list of volunteer tasks and needs should be created by the conference committee. At the same time a list of potential volunteers can be generated. One conference committee member should be designated as the volunteer coordinator. It is suggested that a volunteer training meeting be scheduled immediately prior to the conference to familiarize your

volunteer with the site and the tasks they will be performing. Remember, it is always best to have too many volunteers than not enough. If possible, a 1p36 DSA T-shirt for each volunteer is not only a nice touch, but it will also help identify them to conference participants. Of course a follow-up thank you card to each volunteer should not be overlooked.

13. Special Touches

The difference between a good conference and an unforgettable conference are the little things. (Assuming all the major components go off as planned.) These things are hard to identify specifically, but here are some possible examples:

- A welcoming greeting card in each guest room
- registration goodie bag (complimentary toys, snacks, coupons, toiletries etc -- possibly donated from local stores)
- Decorative name tags
- Room of feeding supplies, formulas, diapers, wipes, and other toiletries etc.. (all complimentary)
- having a large area open at off hours where people can gather for social time

14. Evaluation and Follow-up

Included in the conference packet and available at the registration table should be a simple yet effective evaluation/feedback form (the board can help you with creating one). Announcements should be made throughout the conference encouraging the use and value of this tool. This feedback is beneficial to future conferences as it will provide valuable information as to what to improve upon and what to keep the same. Evaluations should be reviewed by the hosting conference committee and then sent unedited to the board.

The conference committee should have a follow-up meeting to ensure proper thank you and recognition is given to all those who participated. This meeting should be scheduled prior to the beginning of the conference and should take place within one month after the conference. Don't see this as a burden but as a wonderful opportunity to help others who host future conferences.

We all know what a wonderful event the 1p36 Deletion Support & Awareness conference can be. Try to have fun and don't forget to ask others for help if necessary. The board of directors is there for that very reason.

15. Conference Planning Deadlines

- 2 Years before
 - Confirm the host city and Conference Committee Chairperson

- 18 months before
 - Begin to research conference venues and dates for the conference
- 13 months before
 - Have the 1p36 DSA board approve the proposed venue & dates
 - Have the 1p36 DSA board sign the contract with the venue
- 1 Year before
 - Announce to the group the host city, conference dates and venue.
- 9 Months before
 - Begin contacting potential speakers
- 6 Months before
 - Establish a preliminary conference agenda
 - Finalize and get the conference budget approved
- 3 Months before
 - Finalize conference agenda
 - Post conference agenda to the group
 - Begin taking conference registrations
- 1 Month before
 - Close online registration (optional in-person registration could be considered)
 - Print handouts
 - Purchase attendee goodie bags, speaker gifts and other conference materials

16. Sample Project Task list

Listed below are potential projects and task lists that may be needed during the planning of the annual conference. These different projects and tasks are to give the conference committee a starting point in planning all the things that need to be done to put on a successful conference

Travel

- - Ground transportation (outings, sightseeing, field trips)
- - Car rentals (potentially negotiate a reduced rate for the group from the airport)
- - Hotel registration
- - The local visitors bureau is also a good tool for area activities, pamphlets of local attractions and can also assist in reserving your hotel and help to negotiate a rate.

Workshops/Speakers

- - Keynote speakers
- - Schedule of workshops/titles/selections
- - AV equipment needs (work with hotel)

- - Speaker confirmation forms
- - Workshop description write-ups
- - Room assignments and set-up
- - Attendance Limits?
- - Length of sessions
- - Follow-up forms
- - Speaker introductions

Child Care/ Sibling Care

- - Staffing/nurse care
- - Sibling outing selection/permission forms/ transportation
- - Chaperons for outing
- - Materials and supplies: diapers, toys, crib, etc.
- - Registration system/form
- - Information packets
- - Room set-up
- - Schedule of hours

P/R, Advertising

- - Media/press coverage, press releases
- - Conference brochure and registration packet
- - Printing
- - Posters/flyers
- - Letters of support

Fundraising

- - Organization of events
- - Staffing events
- - Donations
- - Donations in kind/goods
- - Work with Budget/Treasurer
- - Registration
- - Concession, T-shirts, etc.

Budget/Treasurer

- - Develop budget expenses
- - Work with fundraising on income budget
- - Bookkeeping for income/expenses

Audio/Video needs

- - Video taping of conference
- - A.V. needs of speakers
- - Audio and/or video taping of workshops
- - Photography

Entertainment/Sightseeing

- - Tours pre/post conference
- - Concierge (self-appointed if not provided by hotel)
- - Local attraction (restaurants, night clubs, amusements parks)
- - Outing night/child care

Medical Needs

- - Contact with local hospital
- - Emergency procedures
- - Emergency contacts

Registration

- - Printing/conference packets
- - Fees
- - Pre-registration incentives
- - Advertising
- - Badges
- - Set-up/staffing
- - Computer lists

Volunteers

- - Determine needs
- - Establish roles
- - Recruit and train
- - Follow-up thank you letters

17. Presenter request form

Presenter Request Form

Presenter: _____ **Please return in enclosed envelope:**
Address: _____ **by May 30th**

Title: _____
Name for Badge: _____
Phone: _____ Fax: _____ E Mail: _____

Short Biography for Conference Booklet:

Topic: (Brief Description of your presentation for conference booklet)

Equipment Request:

Laptop computer: _____ Overhead Projector: _____ Screen: _____

TV _____ DVD player _____ Easels _____ Flip Chart _____

Other: _____

Preferred Room Set Up (We will do our best to meet your needs):

Classroom Style _____ Theater Style _____ Circle of Chairs _____