

TABLE OF CONTENTS

1.0	INTRODUCTION
2.0	CONFERENCE GOALS & OBJECTIVES
3.0	PRE-CONFERENCE FOUNDATIONS
	3.1 Conference Title
	3.2 Site Selection
	3.3 Selecting a Date
	3.4 Steering Committee Organization
	3.5 The Givens
4.0	CONFERENCE PLANNING TIME LINE
5.0	BUDGET & FUNDRAISING
6.0	HOTEL & TRAVEL
7.0	PROFESSIONAL FORUM
8.0	MEDICAL CLINIC
9.0	PICNIC
10.0	RYAN CANTRELL MEMORIAL BALOON RELEASE
11.0	WORKSHOPS AND SPEAKERS
12.0	CHILD CARE
13.0	VOLUNTEER STAFFING
14.0	ENTERTAINMENT
15.0	PERSONAL TOUCHES
16.0	EVALUATION AND FOLLOW-UP

S. O. F. T. CONFERENCE PLANNING MANUAL

1.0 INTRODUCTION

This manual has been put together to help S.O.F.T Conference committees plan and prepare for hosting an international conference. This manual is not an attempt to dictate content to the extent of replicating past conferences. This manual 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.

S.O.F.T conferences have evolved over the years to the point where we can now identify a consistent and standard format that seems to work best for us. Certain traditions and activities have developed and these are identified as a list of “Givens.”

There is one important element of the conference that the board feels very strongly about preserving. We call it the “secret ingredient.” It is the caring, nurturing family atmosphere that sets our S.O.F.T. conference apart from every other type of gathering. 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 or how professional our organization becomes we must never lose sight of the need to include and plan for the nurturing and healing that needs to take place when we come together.

2.0 CONFERENCE GOALS & OBJECTIVES

S.O.F.T. is an international support group for families and professionals interested in the care of children with Trisomy 18, 13 and related disorders. S.O.F.T. is dedicated to enriching the family experience and providing nurturing and care both during and after a child’s life. An annual conference is held by a host chapter and families and professionals from around the world to exchange information, ideas, scientific data, and share the family experience. 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.

S.O.F.T. CONFERENCE PLANNING MANUAL

The seven purposes of S.O.F.T. as stated in the BY LAWS (article III Section 1) should serve as guiding principles for developing a thorough conference program:

Section 1. The Purposes of this organization are:

- A. To advocate for the realization and enhancement of the full spectrum of human and civil rights for persons with Trisomy 18, 13, and related disorders.
- B. To address the social policy issues and conditions that affects the growth and potential of persons with Trisomy 18, 13, and related disorders.
- C. To encourage research related to Trisomy.
- D. To promote the principals of normalization and to humanize and dignify all human services upon which persons with Trisomy 18, 13, and related disorders rely.
- E. To promote public awareness and a better understanding of Trisomy syndrome.
- F. To promote an active and progressive relationship among persons concerned with Trisomy.
- G. To serve as a clearinghouse for gathering disseminating sound information regarding Trisomy syndrome.

3.0

PRE-CONFERENCE FOUNDATIONS

3.1 CONFERENCE TITLE

The title of the conference will be “The X (number of years) Annual International S.O.F.T. Conference,” S.O.F.T. being an acronym for “Support Organization for Trisomy 18, 13 and Related Disorders.” Any deviation from this title must receive board approval prior to the printing and dissemination of any promotional materials.

3.2 SITE SELECTION

Selection of location (city & state) will be made by the S.O.F.T. Board Of Directors following a review of proposals submitted by interested hosts at least 24 months and no more than 60 months prior to the month of the conference.

Interested host sites must fill out an application (see enclosed document and sample proposal) and submit a written proposal for board review at the annual board meeting at conference. It is strongly recommended that the potential Steering Committee's Coordinator make an oral presentation at the board meeting when the proposal is being reviewed, and answer any questions or concerns of board members. Written correspondence from the board president following the board meeting will confirm or deny the formal application.

Site locations should:

- Adequately serve the logistical needs of a minimum of 300 people
- Be easily accessible to the needs of our children (handicap access etc.)
- Be accommodating to family groups and individuals
- Be priced to reflect the profile of S.O.F.T.'s average number/attendant.

3.3 SELECTING A DATE

The International S.O.F.T. Conference will be held in the summer, preferably in the months of July or early August unless special circumstances occur which would make changing the date more advantageous of S.O.F.T. members.

The workshop should be a minimum five days in length and should follow this format:

- Begin on Wednesday with registration, the Board of Directors annual meeting, Chapter Chair training seminar
- Thursday is registration, the Professional Forum, the medical clinic for children with Trisomy and related disorders, and ends with an evening reception (welcome dinner)
- Friday is registration, keynote address opening ceremony, workshop sessions AM and PM, sibling outing PM.
- Saturday exhibits and concurrent workshop sessions AM only, picnic and memorial balloon launch PM
- Sunday non-denominational church service AM, closing ceremony, election, awards presentation, farewell.

Slight changes can be made to this schedule, such as adding a day for workshops or switching clinic and workshop days with approval of the president.

3.4 STEERING COMMITTEE ORGANIZATION

The Steering Committee should be made up of a chairperson (s) and subcommittee chairpersons. The conference chairperson's responsibilities are to coordinate the overall planning and preparation of the conference. Direct responsibilities include: submit application and proposal to Board of Directors, set meeting times, locations and agendas, appoint subcommittee chairs, negotiate and sign contract with hotel, travel agent, scientific session/medical clinic, picnic site (if necessary), acquire 501C3 status and incorporation of local chapter (mandatory). Report to Board of Directors Conference Committee through regular written reports and/or phone contact. Em cee the conference itself.

The chairpersons of each subcommittee are responsible for: Completing tasks as assigned by conference chair and/or Steering Committee, attending all scheduled Steering Committee meetings for regular reports, and attend the conference in an active and supporting role.

SUGGESTED SUBCOMMITTEES AND ASSOCIATED TASKS

- Travel
 - Travel agent contact - optional (contract signed by chair of conference)
 - Airport transportation
 - Ground transportation (picnic, clinic, outings, sightseeing, field trips)
 - Car rentals
 - Hotel registration (may be part of travel agency contract)
 - 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.

- Professional Forum/Clinic
 - Clinic sessions (see suggested list of doctors/specialists)
 - Hospital/medical institution site visit
 - Reception/buffet lunch
 - Recommend doctors/specialists who have had contact with Trisomy children

- CME and CMU credits
- Schedule/agenda for professional forum
- Contact John Carey to coordinate abstracts, speakers at professional forum
- Promotion for professional forum

➤ Picnic

- Site selection (in conjunction with balloon release site)
- Food choices/preparation/serving, menu
- Rental/borrowing of tables, tents, grills, coolers, etc.
- Games, activities, entertainment
- Donations of foods
- Shuttle (coordinate with transportation committee)
- Coordinate with balloon release committee

➤ Balloon Release (Memorial Celebration)

- Site selection (in conjunction with picnic site)
- Announcements/registration
- Rental of helium tanks
- P/A system
- Music selection
- Readings opening/closing
- Printing of labels
- On site coordination (day of)
- CD of appropriate music selection to play during actual release)
-

➤ 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
 - Chaperones for outing
 - Materials and supplies: diapers, toys, crib, etc.
 - Registration system/form
 - Information packets
 - Beeper rental (check-out for parents of children with medical needs)
 - 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
 - Grant writing
 - 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
- A.V.
- Video taping of conference
 - A.V. needs of speakers
 - Audio and/or video taping of workshops
 - Photography

- Entertainment/Sightseeing
 - Tours pre/post conference
 - Work with travel agent
 - Concierge (self-appointed if not provided by hotel)
 - Local attraction (restaurants, night clubs, amusements parks)
 - Music taped and live during conference
 - Outing night/child care

- Medical Needs
 - Contact with local hospital
 - Emergency procedures
 - Emergency contacts
 - Oxygen availability (local medical supply)
 - Home health care hotline

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

- Volunteers
 - Determine needs
 - Work with all committees
 - Establish roles
 - Recruit and train
 - Follow-up thank you letters

3.5 THE GIVENS

Over the years participants of national and international S.O.F.T. conferences have come to expect a certain level of quality and content. It is expected that each conference will have the following list of “givens.” This list is not meant to standardize certain aspects of the conference to ensure continuity from one conference to another. The “givens” for a successful conference include:

- ✓ Scientific symposium/session (usually hosted by the medical clinic site)
- ✓ Medical clinic for children with Trisomy and related disorders
- ✓ Annual Board of Directors meeting
- ✓ Chapter chair training seminar (formerly chapter chair luncheon)
- ✓ Concurrent workshop sessions
- ✓ Exhibit area (memory room)
- ✓ Founding parent Kris Holladay presentation
- ✓ Awards and recognition
- ✓ Sibling outing
- ✓ Picnic
- ✓ Memorial balloon release
- ✓ President’s address
- ✓ Keynote address
- ✓ Care and share session
- ✓ Sib and SOFT kids daycare (separate if possible)

4.0 CONFERENCE PLANNING TIME LINE

24-36 Months ahead: (2-3 meetings)

- Initial chapter meeting to discuss plans to host a conference
- Recruit preliminary steering committee members to prepare application and proposal to S.O.F.T. board
- Initial contact and tours with prospective hotels and medical institutions (for clinic)
- Submit written application and proposal to S.O.F.T. board at least one month prior to annual board meeting at conference.

12-24 months (4-6 meetings)

- Acceptance of proposal from Board of Directors to host S.O.F.T conference
- Sign contract with hotel
- Develop budget and fundraising strategy
- Confirm clinic and professional forum site with contract or letter of commitment
- Search and confirmation of picnic and balloon release site
- Contact with medical advisor, Dr. John Carey, regarding format of professional forum. (scientific symposium)
- Begin public relations and advertising
- Initial contact with keynote speakers and some workshop speakers
- Development of tentative conference agenda
- Develop a balanced list of workshop topics
- Select travel agency to coordinate transportation and hotel registration
- Prepare quarterly reports to conference committee board chair

6 mos – 1 year (6 meetings)

- Fundraising efforts in full swing
- Press releases, contact with local media concerning conference, stories of local families
- Refinement of conference agenda
- Contract with audio visual service
- Begin recruiting volunteers and key staff (i.e., nurses, caterer, day care coordinator)
- Prepare exhibit and promotional materials to set up at conference (the conference prior to yours)
- Prepare quarterly updates to conference committee board chair

2 - 6 mos (8-10 meetings)

- Prepare promotional packets and media blitz
- Prepare registration materials and conference packets
- Submit registration materials to S.O.F.T. newsletter editor
- Continue with final fundraising events
- Send out pre-registration packets with clinic information
- Confirm and order all supplies for day care, picnic, balloon launch, S.O.F.T. merchandise, etc.
- Send out confirmation letter to volunteers
- Set-up schedule for volunteers
- Finalize agenda, speakers, room assignments, AV equipment for clinic, professional forum, workshops.

A final meeting should be set two weeks or so prior to conference to walk through everything from registration to closing.

5.0 BUDGET/FUNDRAISING

Developing a budget will be one of the first tasks of the conference Steering Committee. A working budget is a valuable tool for keeping control of expenses and tracking income. The treasurer of the committee will be responsible for putting the budget together (with input from each subcommittee) and bookkeeping and regular reports.

Developing a budget is not a difficult or magical process. Each subcommittee will be responsible for estimating expenses in their given area. A list of who will combine each subheading into an overall preliminary working budget. The enclosed sample budgets may be helpful to review, but total expenses vary widely, so don't get locked into a particular reconvened number. A big budget does not guarantee a successful conference. Also keep in mind that everyone on the Steering Committee will share in the responsibility of raising money to meet or exceed expenses.

Fundraising will need to begin soon after formation of the Steering Committee. Again, a well thought out fundraising plan will be a useful tool. Fundraising requires time, advanced planning, promotion, and volunteer labor. Whether it's grant writing, personal solicitation or a raffle, fundraising takes a concerted effort

Here is a list of some strategies others have used successfully:

- Personal letters to friends/relatives/acquaintances asking for small donations in support of our conference
- Grant writing- usually to local foundations, universities, hospitals, and service clubs.
- Silent auctions
- Cash raffles
- Gold outing
- Bowl-a-thons
- Bake sales
- Corporate donations
- Donation in kind (merchandise/service)
(See sample letters of donations)
- Golf tournaments

One of your main sources of income will be the conference registration fee. This fee should be kept “affordable” and has ranged from \$90-\$110 per adult over the past few conferences.

6.0 HOTEL AND TRAVEL

Choosing a hotel site and travel agent will probably be the first important decision made by the conference chairs and Steering Committee. (Usually 12 - 24 months in advance)

Criteria for hotel selection include:

- Adequate number of sleeping rooms
- Layout and size of banquet and meeting space, restaurants, and bathrooms (remember, wheelchairs take much more space)
- Relationship and flexibility with the sales and service staff of hotel
- Catering and food service
- Location- proximity to entertainment, shopping, restaurants, and recreation
- Experience in hosting family type conferences
- Handicap accessible rooms

We recommend visiting 3 or 4 hotels for a tour and discussion of the above criteria. Developing a checklist for comparison of pros and cons will be helpful in making your final decision. Don't be afraid to ask tough questions and introduce them to our organization. Ideally, we should host the conference in a medium size hotel 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.

Downtown? Suburbs? Or out in the country? Keep in mind the site of professional forum, medical clinic, and picnic and balloon release. If the medical institution hosting the clinic is downtown, then a nearby suburb will be fine. Costs will vary widely from downtown locations to suburbs. Usually downtown rates are 25% to 40% higher than suburban, plus taxes and parking costs may add to that figure. While suburban rates may be attractive, often times the hotel is isolated from walking distance to entertainment and eating establishments. Substantial discounts may be offered for booking over the 4th of July holiday or other slow summer times. In '92 Baltimore took advantage of this and we had an ideal downtown location right on the harbor that was clean, safe, and within walking distance of everything, but on the other hand, clinics might be difficult to line up during holidays because of physician availability.

'93 Chicago's priority was to make the conference as affordable as possible to allow more people to attend than ever before. The result was an inexpensive conference in a somewhat isolated location. Both were excellent conferences and good choices given the criteria.

'03 Salt Lake's negotiated with the hotel to have reputable chains donate items for the continental breakfast (muffins from Kroger, cinnamon rolls from Rhodes, donuts from Krispy Kreme) which saved a lot of money on continental breakfast every day.

In the end, comparing hotels is somewhat an apples and oranges game, with no two hotels having the same features. After narrowing the choice to two or three, it's time to negotiate. Things like free meeting space and comp rooms 1 per 50 are standard perks. Ask for breakfasts or refreshment breaks to be thrown in. Don't be afraid to play one against the other or to walk away from an unfair offer.

Finally, ask for references of other family type conferences. Interview the head of key service department to get an idea of the type and degree of friendly courteous service that we should expect.

Other details to think about are availability of refrigerators and cribs. This has presented problems at other conferences.

TRAVEL

The use of a travel agent can help simplify the transportation and hotel registration arrangements. Usually this service is provided at no cost to the conference committee. Their fees being generated by a percentage of each airline and hotel registration. Use of a travel agent should be discussed with hotel management. Lower airline rates may be one perk in using a travel agent. (See enclosed sample letter with uniglobe travel)

7.0 SCIENTIFIC SESSION

As a part of each conference and usually coinciding with the clinic, is a professional forum hosted by S.O.F.T.'s medical advisor, Dr. John Carey. In the past this forum has been a scientific symposium and abstract session to encourage health care professionals, scientists, clinicians, and others to exchange valuable information and aid in raising awareness in the medical field of trisomy 18, 13, and related disorders. In Toronto the format was changed to allow for a discussion on ethical issues related to the diagnosis and care of children with trisomy. To allow for the flexibility in the format of this professional forum, it is suggested to contact Dr. John Carey at least 24 months in advance of the conference to discuss the options and responsibility (or other member assigned by chair) to follow up forum. This includes confirmation to adequate meeting space, recruitment of speakers/presenters, AV needs, ongoing correspondence with host site (usually at same medical facility as the clinic) and Dr. Carey, and the promotion and P.R. for the forum. Included are some samples of contact letters with host site staff, call for abstracts and other promotional letters. Please remember these are only examples; each conference will have to tailor their correspondence accordingly.

8.0

MEDICAL CLINIC

Confirming (in writing) the site of the medical clinic will be one of the first responsibilities of the conference chairs. Confirmation should be made 12 to 24 months in advance. Some of the criteria in choosing a hospital, medical center or university for the clinic include:

- Proximity to hotel (should be within a maximum of a 45 minute commute)
- Familiarity of genetics staff with trisomy disorder
- Level of commitment from medical staff
- Demonstrated past experience in hosting clinics of similar magnitude and complexity
- Willingness to promote this event through hospital's public relations staff
- Adequate resources, staff and facilities to host the number of children attending (generally 30 to 50 children with trisomy)

In the past the clinic has been held at some very prestigious institutions: the Kennedy Krieger Institute, Baltimore, Maryland, Loyola University Medical Center, Chicago, Illinois; Hospital for Sick Children; Toronto, Ontario. Generally large, prestigious institutions will be able to accommodate our needs and be interested in hosting such a unique clinic. Without question our clinics have had an impact on the medical staff of the host institution. The fact that these doctors will see so many of our surviving children in one place at one time will help increase awareness of the Trisomy disorder and the many and varied medical needs that our children encounter. It is probably that many of the attending specialist and physicians at the clinic will have never seen a child with Trisomy.

While the primary benefit of the clinic should be increased knowledge and awareness of our individual children's medical condition, we recognize the important side benefit of educating the local medical community about T-18, T-13, and related disorders. This fact will

make a good “selling” point in discussions with medical staff at potential host institutions. Our experience has been that most large, prestigious institutions will gladly jump at the chance to host our S.O.F.T.. conference as they recognize the benefit of seeing so many children with Trisomy. The reality is it can be a real public relations “feather in their cap.”

For this reason we have never (?) had to pay for renting/leasing the facility, or the attending doctors and specialists time. The contact person and site organizer at the host institution has usually been a doctor and support staff within the genetics department. Obviously the doctors most familiar with Trisomy are geneticists. Their network within the hospital or institution is where contacts for other specialists are made. Doctors and specialists may be invited from other institutions (with your host contact’s permission) especially if they have had positive experiences with Trisomy effected children in your chapter or area.

After initial arrangements have been confirmed, including a walk through site visit of reception area and session rooms, regular meetings or phone contacts should be scheduled to make sure plans are progressing. (See sample letters)

Medical history information of children seen at the clinic will be very helpful for attending physicians. Getting this information out and back as possible will expedite clinic sessions and benefit both the doctor and the “patient” (see samples of documents from 1993 S.O.F.T. conference.

(See Professional Forum section for coordinating with clinic)

Transportation to and from the clinic at the hotel will have to run smoothly to assure that everyone stays on schedule. A schedule of departure and arrival times from the hotel to the clinic should be posted in the lobby and enclosed in conference packets. Several loops of pick-up and drop-off should be arranged and confirmed well ahead of time. Buses or vans should go on a practice run before a schedule is made to determine actual travel times. (Remember to take into consideration road construction and rush hour traffic if applicable.)

The clinic is usually held in the afternoon on the first day of the conference. The following is a suggested list of specialists and physicians that should be available for clinic sessions: Survey of

potential conference participants well in advance may help limit the number of specialists needed for the clinic.

- Cardiology
- Neurology
- Neonatology
- Pediatric surgery
- Anesthesiology
- Urology
- Bowel management
- Ear, nose, throat (otolaryngology)
- Genetics
- C.V. surgery
- Plastic surgery
- Orthopedics
- Gastroenterology
- Ophthalmology
- Audio logy
- Physical therapy
- Occupational therapy
- Dental
- Pediatrics

Sessions lengths should be 25 to 35 minutes and individuals generally see up to 3 specialists.

Day care should be provided at the hotel or at the clinic to relieve the congestion in the reception area.

Some problems encountered in the past clinics include:

- (1) Doctors being called out on emergency (doctors should be notified to have a back-up replacement on call should they not be able to attend)
- (2) Reception area/waiting area too small for accommodating our children and all their equipment.
- (3) Lunch and waiting area combined causing a lot of noise confusion and congestion
- (4) Doctors not staying on schedule; going over the time limit causing a chain reaction of late starts and missed sessions.

- (5) Registration for the clinic not wanting what they originally signed up for or just showing up the day of the clinic without pre-registering.

9.0 S.O.F.T. PICNIC

Usually taking place on Saturday afternoon is the highlight of the conference for many who attend. The picnic provides the festive, family-like atmosphere that allows for families to interact and share. Along with good food (usually of local favorites), entertainment, clowns, magicians, music, games, etc. The picnic is traditionally followed by the memorial balloon release and the site that is chosen should take both the picnic and the balloon release into consideration (see section on Ryan Cantrell Memorial Balloon Release.)

FOOD SELECTION

As with any summer picnic a variety of entrees, vegetables, fruits, side dishes, and beverages are available. Most conference picnics have highlighted local specialty foods: crabs in Baltimore, Chicago style pizza, and corn on the cob in Chicago, etc. Serving 400 to 500 people is always tricky, so consulting with a caterer with experience in serving large groups is a good idea. Volunteers to help with preparation, service, and clean-up is a must. Community service groups are a good source to tap into early in the planning stage. This is a great time to enlist family members as volunteers in food prep, serving, set-up/clean-up, etc.

Transportation should be arranged with a bus company. (Possibly through a travel agent.) Again, smooth running handicap accessible vehicles operating on a continuous loop of pick-up and drop off is a must. A shaded area, shelter (rented large tents) should be available for sun sensitive persons or as relief from heat or rain.

10.0

RYAN CANTRELL MEMORIAL BALLOON RELEASE

Honoring the memories of our children who have passed away, the balloon release has become an important and meaningful tradition. We suggest contacting Steve and Peggy Cantrell for input on this event. The balloon release has evolved into a special ceremony that begins with an announcement at the end of the picnic for those families releasing a balloon to pick-up their balloons at a given location. All other participants gather at the designated launch area. Once all the balloons have been handed out, the ceremony opens with a welcome and a specially chose reading or poem. Directions are given on releasing procedure and individual names are read off one by one. Specially chosen background music plays continuously throughout the ceremony. Once the last balloon has been released, participants gather in a closing and final word.

Site selection should be adjacent to picnic area in large open field clear of wires or trees or any obstructions. The equipment needed is an appropriately sound P.A. system with microphones and tape deck. Helium tanks, balloons, ribbon, extra name cards. Registration materials for the balloon release should go out with pre-registration packets and also be available throughout the conference at the registration table (see enclosed sample registration form)

11.0

WORKSHOPS AND SPEAKERS

The goal of each conference is to provide a wide range of topics to insure that all participants, whether professional, grandparent, grieving parent, sibling, surviving child, or prenatal-diagnosed parent, will have meaningful options to choose from. Speakers at workshops are usually drawn from regional contacts and a list of topics brainstormed from the conference Steering Committee. Keynote and specialty speakers (general sessions) usually include founding parent Kris Holladay, Medical Advisor John Carey, current S.O.F.T. President, Past President, along with a regionally or nationally known specialist to give an international or motivational keynote address. Contact should be made with S.O.F.T. President and/or board conference committee chair when developing your list of workshop speakers or keynotes.

When developing your budget for speakers, please keep in mind the costs incurred for nationally-known speakers including travel costs and comp rooms. Develop a standard honorarium for workshop speakers- some you will have to pay- others will offer their services free. Enclosed is a sample workshop speaker confirmation/information form/letter. Also enclosed is the list of workshops offered at the '93 Chicago conference, and the 2003 conference in Salt Lake.

12.0

CHILD CARE

Child care is an essential element in a smooth running, successful conference. Knowing that S.O.F.T. conferences are often family vacations, you can expect to have many children staying at the hotel. The need for child care during the clinic session, workshops, general sessions, and for evening "getaway's," is great. We strongly suggest to have a registered nurse or someone with some medical background on staff at all times during day care hours. You may consider (hiring) staffing the child care room with special needs- workers to allow mom and dad to "go out on the town."

It is important to communicate to the hotel staff (even before signing of the contract) that this will be a family conference with many children attending. Also the staff should be aware of the fact that we will be having a full-blown child care facility (room) on site during the conference. The day care room should be large enough to section off and have a separate sleeping area/play area/changing area/and with bathrooms close by. Ideally this room should be on the same floor and near the banquet and break-out rooms. We strongly recommend consulting with a day care operator for guidance in setting up the day care room and stocking it with supplies. Assistance with a check-in/check-out system and medical staffing with competent workers cannot be underestimated. The quality of the child care can make or break the conference. It is important that parents attending workshops not only have the option of child care, but that they feel confident and comfortable with leaving their child in the child care room. In Chicago, parents were allowed to check out pagers so contact could be made with them whether on or off site. The schedule of child care hours should be listed in the conference packet and posted outside the child care room. In the past, the child care room was closed during mealtime.

Lastly, security should be worked out ahead of time with hotel staff. In addition, a cleaning schedule of the room should be agreed on with staff.

13.0

VOLUNTEERS

Prior to and during the conference itself, there will be many tasks needing volunteer assistance. Depending on your steering committee alone to accomplish all the work is not at all realistic. The 1993 conference in Chicago depended on over 50 volunteers in addition to the Steering Committee. Most of these volunteers were relatives and/or friends of committee members along with one service club and local youth church groups.

Several months prior to the conference, a list of volunteer task and needs should be created with input from each subcommittee chair. At the same time a name list of potential volunteers can be generated. One Steering Committee person should be designated as volunteer coordinator. Three-six months prior to the conference, a response letter should be sent to potential volunteers including a list of specific volunteer duties and times (see enclosed sample letter to use as a starting point.) Confirmation with any service club volunteers (Lions Club, Jaycees, etc.) should probably be made 6 to 12 months ahead. It is suggested that a volunteer training meeting be scheduled immediately prior to the conference to familiarize your volunteers with the site and the tasks they will be performing. The main areas of need for volunteers at the conference are:

- Registration
- Vendor tables (S.O.F.T. T-shirts, mugs, hats, etc.)
- Day care/child care
- Chaperone at sibling outing
- Picnic and balloon launch
- Conference set-up/take down
- Transportation/shuttle drivers
- Clinic registration/reception hosts

On-site check-in for volunteers during the conference along with a written description of the tasks they are performing will be helpful. Each subcommittee chair should have a name list of the volunteers helping at their "station/area." If you can afford it, a T-shirt for each volunteer is not

only a nice touch, but will also help identify them to conference participants. Of course a follow-up thank you card to each volunteer should not be overlooked.

14.0 ENTERTAINMENT

Entertainment is primarily provided during Thursday night reception, sibling outing, Saturday picnic, and any other on site functions or field trips the Steering Committee chooses.

Thursday night reception could be a live band, magician, juke box or D.J., slide shows and videos might also be considered, or even an author or motivational speaker who speaks about experiences with handicapped children. Sibling outing should include children age 5 and up and usually travels to a nearby amusement park, children's museum, zoo, park, pool, or other recreation facility. The picnic has varied from entertainment at a designated space and time to a more free roaming variety of performers (clowns, face painters, jugglers, magicians, puppeteers.) Also at the picnic is a variety of game options from volleyball and basketball, to relay games and kickball. Keep in mind the picnic is a time for families to relax and socialize so entertaining should be an option and secondary focus.

We suggest limiting field trips and outings to no more than two offerings. Contacting your local department of tourism will provide you with a place to start in your planning of these events. If you schedule evening outings you may want to consider child care.

15.0 SPECIAL TOUCHES

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

- A welcoming greeting care, fruit basket, bouquet of flowers in each guest room
- Registration goodie bag (complimentary toys, snacks, coupons, toiletries- possibly from donation in kind)
- Decorative name tags and table displays
- Care and share table for photo albums and memorabilia
- Room of feeding supplies, formulas, diapers, wipes, (all complimentary)
- A large reception suite open at off hours where people can gather for social time
- A personal recorder for each family at clinic to greet, escort, and take notes during clinic sessions

Appoint a Steering Committee member to coordinate and assign tasks

16.0 EVALUATION AND FOLLOW-UP

Included in the conference packet and available at the registration table should be a simple yet effective evaluation/feedback form.

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 chairs and then sent unedited to the board conference committee to insure that the same mistakes aren't repeated next time.

The Steering Committee should have a follow-up meeting to assure 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 it as a burden but as a wonderful opportunity to help others in your situation. We all know what a healing event the S.O.F.T. 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.