



Strollathon Manual

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Overview

What is a Strollathon?

A Strollathon is our version of a walkathon and the participants are called Strollers and Rollers. The Strollathon is a fun-filled, leisurely walk to raise money for a cause dear to our hearts - Rett syndrome. It's not a competitive sporting event. We want Strollers and Rollers of all ages and abilities to have fun and participate at their own pace.

A Strollathon is much more than a walkathon. It's an outdoor party, with entertainment, refreshments, activities and surprises; all incorporating a relaxed but invigorating Stroll and Roll for the attendees.

All of the proceeds from this event will directly fund the three pronged mission of IRSF; Research, Advocacy and Family Support.

How does a Strollathon work?

The Strollathon planning committee recruits persons to be **Team Captains**. In turn, the Team Captains recruit participants - **Strollers and Rollers** - to collect donations from their friends, families, neighbors and co-workers. Money is collected as a flat donation and then turned in on Stroll Day, which is held rain or shine.

The bulk of the funds raised will come from the Strollers and Rollers. A Strollathon has the potential to have hundreds, even thousands, of participants, all of whom are generating donations.

Another way a Strollathon raises money is through donations from generous corporations and organizations - we call them **Partners**. Many Partners may also opt to field a team, thus increasing their organization's financial support.

Does a Strollathon really have potential to raise a lot of money?

Absolutely! You may think there are already several walkathon events in your area and that another one simply can't be successful. Think again! A walkathon may not be an original idea but it is a solid and proven way to raise money. That's why there are so many of them! You may have a small amount of competition for corporate partnerships within a community but there tends to be very little overlap among participants or among individuals who are solicited for donations.

You may also think that the Rett community is so small that a Strollathon doesn't have a chance of attracting significant interest and participation. But events like the IRSF Strollathon are successful because they attract the support of people outside the specific disease community that receives direct benefit.

Rett syndrome is a great cause that deserves to be supported. There are many relatives, friends, co-workers, teachers and classmates who will welcome the opportunity to raise crucial funds. Many organizations that support rare disease research (like cystic fibrosis) have established very successful nationwide walkathon events.

Do I have what it takes to plan a Strollathon?

First and foremost, Strollathon Chairpersons need to be self-motivated and well-organized, focused, and possess a good attention to detail. They need to be outgoing and well-connected in their community. If you're a team player, loaded with enthusiasm and excited about improving the lives of those affected by Rett, then you are the perfect person to Chair a Strollathon.

I want to Chair a Strollathon. Now what do I do?

Welcome aboard! As a Strollathon Chairperson you are instrumental in recruiting a Planning Committee and Team Captains, soliciting corporate Partners and keeping everyone abreast about the details of Stroll Day.

Additionally, you are responsible for organizing all of the logistics for the day such as identifying the walk site and route, securing refreshments and collecting funds. **You will need to work closely with the IRSF administration. They will help you step by step!**

We won't tell you that your job will be easy but we do promise that it will be one of the most heart-warming and rewarding achievements you could ever imagine.

A few basics

There are a few basic principles about the Strollathon that you and your committee members will need to keep in mind throughout the planning process. To ensure a successful event, refer to these basics often and remind your committee of them frequently:

- The main goal of a Strollathon is to raise money for Rett syndrome. There are important secondary goals which can be achieved through the Strollathon - such as increasing awareness of Rett syndrome within the community - but such secondary goals cannot replace or overshadow the main goal of raising money.
- The bulk of the money will be raised by the individual participants who are members of Strollathon teams. **Thus, the primary goal of the committee should be to recruit and motivate Team Captains and participants.** The committee members should remain focused on team building and not get overly bogged down in important but secondary activities including PR and event logistics planning.
- The important work of a Strollathon – fundraising - takes place before the event. The event is planned such that it can be successful even if weather causes people not to attend. Keep in mind that the Strollathon will be held rain or shine. Although good attendance at the event is important, participants who haven't engaged in fundraising prior to the event don't contribute significantly to the success of the event. For example, a newspaper article or TV story that causes people to attend the Kickoff Gathering and become Team Captains is to be considered an important coup; an article or story that

causes people to show up on Stroll Day without having raised money is positive, especially for next year, but not nearly as important.

- The Strollathon experience has to be fun and pleasurable for everyone involved. Strollathons are most successful if they become annual events in a community. And, if the Strollathon experience is positive this year for all participants (Partners, Committee Members, Team Captains, Strollers and Rollers), they will all renew their support next year, allowing next year's organizers to focus on growth. We would expect our Strollathons to grow significantly year by year.
- Chairpersons and Committee Members must create a spirit and maintain a focus - for everyone involved - on raising money and having fun.

A word about finances

The number one thing to remember about planning a Strollathon is that every dollar of proceeds will fund research, advocacy and family support. **Strive to get goods and services donated or at reduced costs.** That will mean more money for IRSF.

IRSF will underwrite the expenses of staging your event that will then be deducted from your final amount raised. IRSF can issue direct payments with advance notice or will reimburse with proper documentation. Be sure to save your receipts.

Committee Members should try to get donations of as many things as possible, especially food and entertainment. Members should focus their efforts on securing such donations from people and businesses with which they have a pre-existing connection. Keep in mind that companies that donate gifts-in-kind may use the amount of their donated items toward a Partnership level.

Below is a sample budget which should serve as a guideline for your event. During the early planning stages the Chair should develop the event budget with the input of the committee members and a staff member of IRSF. This manual will give you an idea of all the necessary line items. It goes without saying that the goal is to get as many items as possible donated. Once your budget is set, it should be discussed with the IRSF administration.

Budget

Event registration fees, insurance	\$ 500
Kickoff Luncheon	\$1,000
Printing of materials	\$4,000
Prizes, t-shirts, etc	\$3,500
Stroll Day	\$1,000
Miscellaneous (mailings, supplies, etc.)	\$2,000
Total	\$12,000

****Please note: All printed materials such as collection brochures, posters, t-shirts, hats, folders, etc. are paid for and provided by IRSF. Fees and insurance are also covered by IRSF. Please speak with IRSF prior to making any final plans.***

Section 1

Selecting a date and location

The great thing about a Strollathon is that it can be held almost anywhere at anytime of the year. Of course, you will need to consider your area's climate and choose your date accordingly. Most Strollathons are held in the spring or fall. Planners in Northern locations with longer winters may want to opt for late Spring or early Fall dates while those in Southern locales should probably hold their event in early Spring or late Fall.

Almost every event is held during a weekend. If asked, about half of participants will prefer to Stroll and Roll on a Saturday while the other half will prefer Sunday. Keep in mind that most people will partake of the usual weekend activities such as sporting and family events, shopping and religious services. You won't be able to satisfy everyone who wants to participate but most people will be glad to adjust their routine to support such a worthy cause.

Determine a date for your Strollathon and give yourself at least 6 months for planning. Many Committees prefer 9 or even 12 months to plan a Strollathon. Check for conflicting dates with other IRSF events or other large events in the area like sporting events, concerts and religious holidays.

Strollathons should be conducted in a place that is safe, easy to access from every direction and where traffic is restricted but parking is accessible. Possibilities include state and city parks, college campuses, downtowns and shopping mall and hospital parking lots. Check with other organizations in your area to see where they hold their events. Contact a local running or walking club for advice. You'll find that there are many people who have organized similar events ready to give you the benefit of their experience if you just ask.

Some things you'll want to consider when scouting sites:

- Availability of regular and handicapped parking
- A relatively flat (preferably paved) route with no proximity to traffic or hazards such as water and drop-offs. And the route should provide some challenge to everyone but short enough to accommodate all participants of varying ages and physical abilities. We recommend at least 1 kilometer or 1 mile but no more than 3 kilometers or 3 miles.
- A place for a start/finish line that is adjacent to the staging area which must be able to accommodate registration, entertainment, etc. as well as hundreds of Strollers and Rollers.
- Accommodations such as tables, a stage, toilets. If not provided, the site must permit you to rent those needed items. The location must also allow you to provide refreshments.

Once you've selected the site, contact local authorities to secure permits, insurance and police involvement. Permits may require a fee with submission. Proof of liability insurance will likely be required. Please check with the IRSF office regarding insurance requirements. IRSF will work with you to obtain necessary documentation. You will need to contact the site's police department if streets will need to be closed or traffic stopped while Strollers and Rollers cross. Many police departments have special task forces or traffic police just for such events. Ask if the police or traffic control officers will donate their time. Remember to always keep the safety and needs of your participants in mind while planning the walk route.

Section 2

Recruiting Committee Members and first meeting

You will want at least two to three enthusiastic and dedicated Committee Members to form your core group. You may even want to ask someone to co-Chair the event. Your committee members should be a diverse group, bringing their individual talents, contacts and experiences to the table.

To prepare for your first meeting, have on hand sample materials from previous Strollathons – Partnership Opportunities folders, Team Captain folders, Check-in Forms, Kickoff Luncheon invitations, etc. If this is the first Strollathon in your area, IRSF will provide you with these materials from another city's Strollathon.

As you hold your first meeting, it is important to keep in mind and to stress to your Committee the importance of focusing on one step at a time. The job of holding a Strollathon, especially the first one, may seem overwhelming at times. But if you follow the timeline and keep focused on each step, you'll see how easy and organized your event will be.

Keep the emphasis on our number 1 and number 2 goals: to raise money and to have fun. As enthusiasm builds at this and subsequent meetings, there may be a tendency to be sidetracked by other issues. From time to time, you may need to remind everyone of the Strollathon's primary goals.

Remember to take notes at this and all your meetings. You'll be referring to them often.

At your first meeting:

- Explain the process and details of planning a Strollathon. Review the sample printed materials.
- Choose a Strollathon date and location, if not already chosen.
- Identify committee members' strengths. For instance, who knows many of the community leaders you'll be calling on to form teams? Who is related to the CEO of a big corporation? Who has a relationship with area Rett families? Whose spouse works for a water bottling company? Whose neighbor is a local celebrity? Who has experience with the media?
- Decide if sub-committees should be formed (i.e. entertainment, Partnerships, publicity, etc.) and who should Chair them.
- Choose a Kickoff Gathering date and assign someone to approach possible sites and get prices.
- Assign someone to approach area printers about donating services or providing reduced costs.
- Stress that everyone needs to begin identifying possible Partners. Once the Partnership Opportunities folder is ready to go, approach your contacts.
- Have everyone begin compiling their Kickoff Gathering guest list, which will include possible Team Captains and Partners.
- Establish a Strollathon mailing address, phone line for voice and faxes, and email address. You may use your personal contact information or create new ones.
- Keep everyone focused on the tasks at hand. Now is not the time to decide what to offer for refreshments or what to name your team. If something being discussed may be of use later, make a note of it but steer the conversation back to this meeting's focus.
- Make sure everyone has exchanged phone numbers and email addresses.

- Before adjourning, make certain everyone knows what the three main things they need to focus on after this meeting: identifying and recruiting Partners, compiling their Kickoff Gathering guest list, and “talking up” the Strollathon to everyone.
- Make sure everyone has exchanged phone numbers and email addresses.
- Develop budget

The day after your first meeting, write a group email to your Committee thanking them for their enthusiasm and ideas. Let them know you’re glad they’re on board and that you value the time and work commitment they are making to the Strollathon. Recap the main points at the meeting. Reassure them that you’ll be in constant contact.

Sample email

Dear committee,

Wow! What a great meeting we had last night. I am so thankful you all have embraced the idea of a Strollathon so enthusiastically. After hearing all your feedback, I am convinced this Strollathon is going to be a huge success! I can’t wait to get started.

Remember, we should all begin making lists of our corporate contacts to approach as Partners, as well as our lists of people we want to recruit as Team Captains.

Also, if you know of anyone who would be interested in joining our committee, please send me his or her phone number and email address. I will contact them ASAP.

Our next meeting will be Tuesday, Nov. 15 at 7 p.m. in the library’s community room. Until then, I will send out a weekly email update on Mondays so we all can keep in touch.

Thanks again, everybody. Your help with this project will make a huge difference in the lives of our girls.
Nancy

Section 3

Recruiting Partners

Partners are the larger donors (\$500 and up) who receive certain publicity and prize benefits in return for their donations. Some people on the Committee may have many ideas of whom to approach while others may not. Committee Members should focus on working their connections – mass mailings to organizations in which there is no personal connection rarely yield Partnerships.

From the people you have a relationship with, don't rule anybody out. Partners come in all forms - local small businesses (retail and service, including law offices), local branches of national or regional businesses (e.g. brokerage houses, banks), schools (or school PTAs), service providers (e.g. physicians, speech and language therapists, physical therapists, etc.), clubs (e.g. Kiwanis, Lions), media (radio stations, TV stations, newspapers), health clubs, and sometimes local foundations, families or individuals. Some Partners may also form Strollathon teams (in addition to making donations), but this is not necessarily the case.

Committee Members should focus on people they know. If your neighbor or friend is affiliated with a business or organization that might have an interest in a Partnership, please approach him or her. *And definitely approach your employer.*

As you approach your contacts about Partnerships, please keep three things in mind:

1. Rett syndrome/IRSF is an extremely worthy cause.
2. Most of the individuals you will solicit are used to being solicited, are in the habit of making donations to worthy causes and may appreciate your bringing to their attention a particularly worthy cause.
3. There are some great public relations benefits that accrue to a Partner.

You will need to put together Partnership Opportunities folders with your solicitation materials, including the Partnership Opportunities brochure, a letter from the Chair, and materials about Rett Syndrome and the IRSF. Obviously, the most important piece in the packet is the Partnership Opportunities brochure that lists the levels of Partnerships. You and your Committee need to become familiar with the levels and accrued benefits. **All of these materials will be provided for you.**

Ideally, you would approach your contact personally, with a packet of materials in hand to leave after your pitch. If personal contact is not feasible, you can send a packet of materials with a cover letter.

Some of the Partnership levels are time critical because of the time schedule for printing participant brochures so potential large donors should be approached as early in the planning process as possible. You will want to receive a commitment from Partners at least one month prior to the Kick Off in order to have all logos on printed materials.

Ask someone on your Committee to oversee the Partnerships. This person needs to:

- Keep an organized list of organizations that have been approached and by whom (you don't want to look unprofessional by having two people approach the same company).
- Keep note of what level they have joined the Strollathon.
- Keep track of payment by the Partners.
- Ensure the Partner receives all the benefits accrued as outlined in the Partnership Opportunities brochure.

Section 4

Organizing the Kickoff Gathering*

The Kickoff Gathering may be the most important event in the Strollathon planning process. The attendees of the gathering, guests of IRSF who have been invited because of their potential to serve as Team Captains and to otherwise support the Strollathon effort, will be informed about Rett syndrome and IRSF. They will be instructed and motivated on how to successfully build a team.

The gathering, which is typically held in a private room of a restaurant, hotel or club, and at which food and drink is served, should be informative, entertaining and pleasurable. A buffet-style luncheon is not recommended because the presentations are nearly continuous and it is important for attendees to remain seated and attentive. ***Be creative with your Kickoff! Possibilities include, but are not limited to barbeques, breakfasts, teas, etc.**

The Master of Ceremonies, who will introduce the speakers and the IRSF video, should be carefully chosen for the purpose of maintaining the interest of the attendees and keeping the program moving. The room should contain a public address system and a large-screen television or video projector. **Most of the time the Master of Ceremonies is the Chair.**

Every Committee Member as well as interested non-committee members (e.g. local Rett families) should compile a mailing list of potential Team Captains and potential Partners to be invited to the Kickoff Gathering. **The Gathering is free to all interested parties.**

A Committee Member or Members should be in charge of organizing the Gathering and the mailing list for the Kickoff Gathering invitations. The IRSF office can provide you with its mailing list of Rett families in your area.

The Kickoff Gathering will be held approximately 8-10 weeks prior to the Strollathon. This timeframe has been determined to give the Captains enough time to recruit many participants and solicit donations without losing interest.

Have sign-up sheets at the Gathering for guests to provide their contact information (name, address, email address and phone and fax numbers) as they arrive. This will come in handy for follow-up.

In the days immediately following the luncheon, mail out folders to all who could not attend but indicated they were interested in forming a team, as well as the no-shows.

Add any new names/information from the sign-in sheets to your database and write an enthusiastic and gracious group email to the Captains. Keep the momentum flowing!

At the Kickoff gathering, potential Team Captains will learn all about the Strollathon and will be given a Team Captain's folder that they can use to recruit and motivate Strollers and Rollers for their Strollathon teams.

The Team Captain folder will contain:

- Guidelines for Team Captains

- A Partnership Opportunities brochure
- Guidelines for a letter-writing campaign
- Collection Brochures
- An IRSF brochure
- A listing of IRSF research awards
- Any other local or IRSF-generated printed materials that focus on Rett, families or IRSF.

The Strollers and Rollers on a team usually consist of family, friends, co-workers, etc. of the Team Captain, and each will solicit sponsorships (i.e. donations) from their family members, friends, neighbors, co-workers, etc., and will participate in the Strollathon.

Strollathon teams are often organization-based (i.e. office teams, school-based, club-based, etc.) neighborhood-based or family based, or some combination thereof. The efforts of Team Captains and the Strollers and Rollers on their teams during the eight weeks or so between the Kickoff gathering and the Strollathon will, for the most part, determine the success of the event.

The Kickoff Gathering will be free of charge to all attendees but the printed invitations will indicate that attendees should be people who are interested in supporting the Strollathon. It is not necessary to secure a commitment of becoming a Team Captain before inviting someone to attend, but you should exercise judgment and only invite those people whom you think might become involved in this way if they are properly motivated at the gathering.

Invitations will be mailed to individuals on the mailing list that the designated person puts together. In addition, invitations can be handed out at meetings of clubs, to parents at schools, etc.

The invitation mailing must take place about five to six weeks before the gathering.

Sample Kickoff Gathering Agenda

The luncheon will last approximately 90 minutes

12:05–12:10 Kickoff host (could be the Chair, a local news personality or celebrity) welcomes and thanks everyone for coming. Briefly describes the purpose of the gathering and the flow of the meeting; reassures attendees that it will end by 1:30 p.m. but that key people will remain afterwards to answer any questions. Remarks on how pleased he/she is to be associated with this Strollathon and how he/she hopes the community will support the event enthusiastically. Mentions his/her exposure to and knowledge of Rett, and its emotional impact on him/her. Expresses his/her conviction as to the importance of this cause.

12:10 –12:40 Lunch (or whatever is on your menu) is served

12:40 Host starts program, introduces Chair or one of the co-Chairs of the Strollathon

12:41- 2:44 Chair welcomes and thanks everyone. Discusses how exciting it is to be involved in the Strollathon, how grateful he/she is to all the committee members and to businesses and individuals who are donating services, including the host, and how hopeful she/he is that a successful Strollathon will raise important funds to support IRSF. Chair then introduces the IRSF video, by which we can all learn more about Rett syndrome and IRSF.

12:44– 2:50 IRSF video

12:50 Host comments on what a moving video we just viewed, then introduces the other co-Chair or reintroduces Chair.

12:51–12:54 Chair or co-Chair describes how he/she became involved with IRSF and what a great organization it is.

12:55 Host states that now is the time in the program to learn in detail how the Strollathon will work and what information is contained within the printed materials that Team Captains and Team Members will be provided. Introduces person who will explain the materials.

12:56 – 1:24 Above person will review the information in the Team Captain Folder and provides detailed description of the process of forming a Team, recruiting Team Members, and soliciting sponsorships (donations).

1:24 Host introduces any dignitaries present.

1:24 – 1:28 Dignitaries announce that they will attend the Strollathon and will serve as a Captain. Describes how excited he/she is to be part of such an important effort.

1:28 – 1:30 Host thanks everyone for coming and reminds them to hand in completed forms on their way out. Tells people they can take extra materials by the door on their way out and that he looks forward to seeing them at the Strollathon.

1:30 – 2:00 Attendees pick up extra materials at the door. Chairs and committee members remain to answer questions.

Section 5

Guidelines for Team Captains

Team Captains are the essential key to a successful Strollathon. The amount of effort and dedication they put forth will directly impact the success of your Strollathon. Make sure you keep in touch with all the Team Captains, offer advice, help and encouragement. You can never thank your Team Captains too many times!

You want as many Strollers and Rollers as possible to participate because every single participant is generating donations. Therefore, you'll need to recruit as many Team Captains as you can and encourage them to build their teams.

Just about everyone you ask to participate will likely be thrilled to be asked to be a Captain. They may even have people in mind who would also like to be Captains. Don't sign anybody up as a Stroller or Roller without first asking them if they'd like to Captain their own team.

This approach will undoubtedly lead to your Strollathon numbers growing day by day!

Types of Teams

Strollathon teams come in various shapes and sizes. Basically, a Strollathon team is a collection of participants (Strollers and Rollers), organized and led by a Team Captain (a very large team may have two or more captains), who raise money for the benefit of IRSF by soliciting fixed donations from friends, family, neighbors, co-workers, and other individuals or organizations. A team can consist of a handful of people or as many as several hundred (as might be the case with a large corporate team).

Generally, teams fall into the following categories:

- **Family/Friends/Neighborhood-Based Teams**
These teams are usually centered on a family that is directly affected by Rett syndrome through a family member or through a close friendship with an affected family. Immediate and extended family members are often team participants, as are friends, neighbors and co-workers. It is not unusual for a family member or friend in a remote location to form a Virtual Team (see below). A family member often serves as Team Captain, and the team name is often based on the name of the person afflicted by Rett Syndrome (e.g. "Julie's Dream Team", "For the Love of Megan", "Ellen's All-Stars", "Hannah's Hope", "Anna's Angels", "Cathy's Cousins", "Friends of Heather", "Jessica's Team", "Team Susie", "Smith Family Team", "Betsy's Block Team", etc.). Letter-writing campaigns are particularly effective with Family/Friends/Neighborhood-Based Teams.
- **School/Service-Provider/Organization-Based Teams**
All schools, whether or not they serve children with developmental disabilities, are candidates for Strollathon team formation. All groups or individuals that provide services to persons with Rett syndrome and other developmental disabilities, including medical offices (e.g. developmental pediatricians, neurologists and other specialists), physical therapy, occupational therapy, speech

and language pathology practices, law offices that practice disability law, financial planners who specialize in establishing special needs trusts, etc., are candidates for team formation. In addition, any organization, group or club with a civic orientation, whether it be the Rotary Club, the Girl Scouts, the Junior League, or a church or synagogue congregation, has the potential to form a team.

- **Business-Based Teams**

A business-based team would typically be formed in support of an employee with a child or relative with Rett syndrome. A business-based team might also be formed as a result of a relationship with a key executive or an owner of a business. Many companies make a practice of encouraging employee participation in civic and charitable activities within the community, whether or not anyone within the company has a personal connection with the cause.

- **Virtual Teams**

While the Captains and the Strollers and Rollers of the Strollathon teams will typically attend the event, it can be very effective to form a Virtual Team. Julia's aunt, who lives 600 miles away, can serve as Captain of "Julia's Traveling Team", and recruit friends, neighbors and co-workers to serve as Virtual Strollers and Rollers. These Virtual Team members can solicit sponsorship donations just as regular Strollers and Rollers would. Instead of handing in all donations on the day of the Strollathon, the donations can be mailed to the Strollathon Committee shortly before the Strollathon. Or, a family in a distant community whose daughter has Rett syndrome can support IRSF by forming a Virtual Team made up of family, friends, neighbors and co-workers.

Team Captain Responsibilities

- Have fun and help make the Strollathon and the activities leading up to it a fun experience for team members.
- Name your team, and communicate the precise team name to all members (be certain, for example, that "Jackie's Team" is not sometimes called "Jacque's Team", or "Team Jackie"). Name consistency ensures that your team receives full credit for the efforts of all members.
- Recruit your team. Recruit as many Strollers and Rollers as early as possible, but continue recruiting until the day of the Strollathon.
- Provide Strollathon brochures to members, but first fill in the team name and Team Captain lines on both the Participant Registration Form and the Strollathon Check-in Form of each brochure that you hand out.
- Set-Up and maintain a team member list, including up-to-date contact information for each member. Find out how to best communicate with each member (email, daytime telephone, evening telephone, cell phone, etc.). Update this list as new members are recruited.
- Hold an initial organizational meeting with the entire team, if possible, to make sure that all members understand the job that needs to be done and how to best do it. Such a meeting, although not required, is well worth the effort if you are in a position to organize it.

- Communicate regularly with each team member. Ask how she or he is doing. Inform less productive members of the successes of more productive members, and share tips regarding what strategies and techniques for fundraising have proven to be effective for others. Provide ongoing encouragement and advice to all team members.
- Submit regular progress reports to the Strollathon Committee with up-to-date information on the number of members recruited and the amounts of sponsorships collected by them. It will be important to the committee to keep this information as current as possible so that smart decisions can be made when orders are placed for Strollathon T-shirts, refreshments, prizes, and to estimate the number of Strollathon Day volunteer workers to be recruited.
- Coordinate the design and production of a team T-shirt, banner, hat, sign, or any other spirit-building element that your team decides to take on at its own expense. Team T-shirts, incorporating your team name, the Strollathon logo, and other colorful and fun design elements, are an especially effective way to build team spirit and motivation.
- Be on the lookout for potential Partners (large donors, particularly businesses and organizations) among your contacts and those of your team members. We also need in-kind donors, particularly for refreshments and entertainment for the Strollathon. Contact the Strollathon Committee when you identify such potential supporters to coordinate approaching them for donations. We will also ask you to be on the lookout for volunteer workers for the day of the Strollathon.
- Post-event follow-up with team members is important to be certain that all pledges are collected and monies sent in, and that all sponsors entitled to matching corporate gifts are following through with the necessary paperwork. Thank them for making your team such a success.

Team Building and Fundraising Tips

- Promote team spirit and identity. Engage the team in efforts that will build team spirit and create a sense of team identity. Design and produce a team T-shirt that all team members will wear at the Strollathon. Develop a team slogan or a team chant or song. Organize an informal team kickoff gathering and another gathering midway through the solicitation process. Communicate regularly with team members and encourage members to communicate with each other to share ideas and strategies. Encourage a sense of competition between your team and other teams.
- Learn and teach why IRSF is so important. Take a few moments to learn about the important work IRSF does and why Rett research is so important, and share your knowledge with team members. This will bring great credibility to the fundraising efforts of your entire team. The IRSF brochure contains excellent information that will be valuable in this regard, as does the RSRF website.
- Set individual and team fundraising goals and communicate these to all team members. **The minimum individual goal should be \$100, the amount that qualifies a participant to receive a free Strollathon T-shirt, but a significantly higher individual goal will be easily achievable by most participants.**
- Develop plans both for recruiting team members and for soliciting sponsor donations. Make lists of potential supporters and decide which function (team member or sponsor) and which method of approach (letter, telephone call, personal visit, etc.) is most appropriate for each one. Consider any

of the following as potential team members and/or sponsors: immediate and extended family members, neighbors, co-workers, friends, members of clubs to which you belong, everyone on your holiday card list, the professionals and merchants who get your business (doctor, dentist, lawyer, accountant, broker, insurance agent, pharmacist, veterinarian, architect, realtor, restaurant owner, landlord, health club manager, dry cleaner, etc.), and anyone whose charitable cause you have supported in the past. Don't limit your list of possible recruits and sponsors to people who live in your community; out-of-town family members and friends might be among your biggest supporters.

- Double your team size by asking every person you recruit to recruit one more Stroller and Roller to join the team.
- Organize a letter-writing campaign and encourage your team members to do the same. For many participants this will be the most productive aspect of their overall fundraising effort. Refer to the Letter-Writing section of this manual for tips and sample letters.
- Host a Strollathon party, and use the opportunity to recruit team members and sponsors.
- Reach out to families, teachers, professionals, support groups, that are touched by Rett Syndrome and other developmental disabilities. Don't forget that scientists believe there may be connections between Rett Syndrome and autism, schizophrenia, and possibly other neurodevelopmental disorders.
- Set a positive example. As Team Captain, you will motivate team members if you are the first to make a donation, the first to develop a personal plan for sponsor solicitation, the first to initiate a letter-writing campaign, the first to approach extended family members about supporting the Strollathon, etc.
- Talk the walk. Tell everyone you know or meet about Strolling and Rolling for Rett research. Look for opportunities to give a public presentation (at schools, clubs, etc.) about Rett Syndrome and the Strollathon, and don't hesitate to ask the Strollathon Committee for help.

A Few Basics of Fundraising

- People give to people, not to causes. There are more good causes than any of us has friends, so we tend to give because our friends/family/colleagues support the cause. **Remember that you are not asking for yourself but you are asking someone to help girls and women struck with a terrible neurological disease.**
- However, people do not like to give to bad causes. Make sure your donor knows that IRSF is a well-run organization doing important work. You should feel that you are doing the donor a favor by providing an opportunity to support a serious organization with a compelling mission.
- Usually people only give if they are asked to give. Unsolicited contributions are rare. If you tell someone you are raising money for an important cause but forget to ask the person for a donation, the chances are excellent that you will not receive a donation.

- Unless you are making your request in writing as part of a letter-writing campaign, it is better to ask for a contribution in person than over the telephone.
- Always make your own gift first. Your donation gives you credibility when you ask someone else for a donation.
- It is best to ask for a specific amount. People like to know what is expected of them. If possible, do your homework in advance and try to determine the appropriate amount to ask a donor to give.
- People are more likely to be insulted if you ask for too little rather than too much. It is flattering if someone thinks you have the potential for a more substantial gift. Don't underestimate how much money someone will donate. If you ask for \$10 and they were thinking \$100, you will likely get \$10 to \$25 instead of \$100.
- Don't apologize for requesting a donation. Most individuals and businesses make contributions to worthy causes, and it makes them feel good to do so.
- After you've requested a gift, don't linger if the potential donor doesn't immediately respond. Silence is not a "no." Don't feel like you have to ramble, fill in pauses or change the donation amount. Rather, suggest a time when you might contact the potential donor to follow up. Then make a quick and graceful exit.
- You should thank a donor as often and as profusely as possible.
- Contributions are often made for their goodwill and public relations value as well as for their tax-deductibility. Some charitable organizations even make donations to other charitable organizations. Do not hesitate to ask any and all organizations to support the Strollathon.

Other ways to raise money and awareness

- Put some brochures on your desk at work. When your co-workers ask what a Strollathon is all about, you can explain and ask for their help. Plastic brochure holders are available at office supply stores.
- Hang a poster on your office wall or bulletin board. Design a badge/button to wear.
- Ask for contributions around pay day or other times donors have cash handy.
- Remember, this is a prepaid walk. Challenge a group of people such as co-workers, workout buddies, bridge club, golf pals, to get involved. Don't forget scout groups, kids' clubs and cheerleaders. Encourage friendly bets to promote team spirit.
- Take advantage of peer pressure. Approach people in a group setting such as before a business meeting, in the lunchroom, following a PTA meeting. Ask people to donate what they would spend on weekly incidentals like movies, dry cleaning, fast food, gourmet coffee. Get them thinking and pass your donation sheet around.

- Ask those you patronize to reciprocate. Ask the manager of the local gas station, grocery store, coffee shop, hair salon, dry cleaner to make a pledge in return for your faithful patronage.
- Remember to use matching gifts. Many companies match their employees' donations to non-profit organizations.

How To Raise A Quick \$500

Ask 10 co-workers for \$10

Ask five friends for \$20

Ask four relatives for \$25

Ask five neighbors for \$20

Ask your doctor, lawyer, hairdresser or personal trainer for \$20

Put in your own contribution

DOUBLE THAT \$500

Ask all your donors to get one person they know to match their contribution.

JUST IMAGINE

- If three of your teammates decide to captain their own team, you'll have added dozens of participants, all generating more donations. (Don't forget to recruit three more participants to replace them on your team!)
- If every Captain sets a goal of recruiting 25 participants, and then each of those participants recruited another.
- If your team has 20 participants and they each raise \$500, together you've raised \$10,000!
- If a team has 30 participants and half raise \$1,000, together you'll raise more than \$15,000!
- How much money together we can raise to fund Rett Syndrome research.
- That if every Team Captain, Stroller and Roller goes the extra mile, RSRF will likely to be able to fund research projects it otherwise wouldn't have been able to.
- Someday hearing the astonishing news that Rett syndrome has been cured and knowing you helped saved the lives of thousands of girls and women the world over!

Spheres of Influence

Think that you don't know anyone who can help? Print out this list to help you think of people in your "sphere of influence" who could be a participant in the Strollathon or make a donation. Don't limit yourself to just these categories! Keep a notepad nearby and write down the names of people or categories outside of this list! Then take a few moments each day and call them . . . you will be surprised how many people will want to help, especially when they learn that it is important to you. Keep track of those who commit and follow up with them.

Dentist	Family Members	Farmer
Doctor	Dry Cleaners	Fashion Model
Obstetrician	Colleagues	Financial Advisor
Pharmacist	Church Members	Fire Chief
Veterinarian	Car Salesman	Fisherman
Accountant	Carpool Partners	Furniture Dealer
Architect	Best Man	Golf Pro
Builder	Ushers	Grocer
Congressman	Babysitters	Industrial Engineer
Insurance Agent	Armed Forces	Insurance Adjuster
Lawyer	4-H Leader	Interior Decorator
Clergyperson	Actor/Actress	Judge
Delivery Person	Air Traffic Control	Lab Technician
Mail Carrier	Anesthesiologist	Librarian
Paper Carrier	Antique Dealer	Lifeguard
UPS Delivery Person	Appraiser	Swim Instructor
TV/Appliance Repair	Art Instructor	Lender
Teachers	Auctioneer	Lithographer
Spouse's Boss	Banker/Teller	Local Celebrity
Sorority Sisters	Best Friend	Mechanic
Store Clerks	Brewery Salesperson	Missionary
Rotary	Broker	Mortician
Lions	Bus Driver	Mortgage Broker
Jaycees	Business Competitors	Motel Owner/Manager
PTA Members	Business Vendors	Motor Home Dealer
Photographer	Carpenter	Moving Van Operator
Pet Store	Caterer	Music Teacher
Parents	Chef	Newspaper Employee
Kid's Friends	Chiropractor	Nurse
Neighbors	Computer Programmer	Office Manager
Maid of Honor	Construction Worker	Police Officer
Bridesmaids	Contractor	Public Relations
Landscaping	Dance Instructor	Realtor
Landlord	Dental Hygienist	Restaurant Manager
In-laws	Dietitian	Scout Troop Leader
Hunting/Camp Pals	Editor	Security Guard
Health Club	Electrician	
Fraternity Brothers	Engineer	

Section 6

Conducting a letter-writing campaign

Although a face-to-face inquiry is the most effective way to raise money, a letter-writing campaign allows you to ask for a donation when such a meeting is not possible. After all, if a friend or family member wrote to you and asked for a few dollars, wouldn't you give a donation to them for such a great cause?

A letter-writing campaign is one of the easiest and most successful fund-raising ideas. The best fund-raising letters come from those personally touched by Rett syndrome - parents, siblings, friends, families, teachers and therapists. You will be amazed at how much money a Stroller or Roller can raise by a simple letter. Letter-writing campaigns for IRSF have raised as much as \$1,000, \$5,000, \$10,000 and even \$20,000!

Encourage every Stroller and Roller, Committee Member and Team Captain to conduct a letter-writing campaign. Imagine if everybody sent letters how much more research money would be raised!

How to Make the Most of a Letter-Writing Campaign

- Speak from your heart; tell your recipients why you are supporting this worthy cause. Try to include a photo with your letter. This is very effective because a photo will help to put a face with the cause.
- Be creative in compiling your list for sending the letter. Send it to family members, friends, co-workers and business associates. Send it to people whose causes you support: the families of Girl Scout cookie sellers, Little League team players, high school band members. Use your holiday mailing list, neighborhood directory, swim team roster, alumni list.
- Don't be shy about approaching vendors, consultants and business people with whom you work. These people may be able to make larger donations because they may be able to make them from their business rather than personal funds.
- Include some information on the promising research on Rett and refer your readers to the IRSF website.
- Enclose a copy of your Strollathon pledge sheet with your personal pledge on it so that everyone knows that you are personally contributing to the cause you are asking him or her to support.
- **Send your letter out at least 3-6 weeks before the Strollathon. Follow up with a phone call or personal visit.**

- Remind them that all donations are tax-deductible and checks should be made out to IRSF. Suggest several monetary increments. People are flattered when they are asked for more money than they usually donate.
- Try to collect the donation before the date of the Strollathon so you can turn it in on that day. Enclose a return envelope if possible, addressed to you, so you know whom to thank personally after the Strollathon.
- Send thank-you notes after the Strollathon to everyone who sponsors you.
- Remember, the more people you target, the more positive responses you are likely to receive. Like any solicitation, it takes a large number of requests to get a reasonable number of gifts. So the more you ask, the more money you will raise to support Rett research.

Sample Letter 1: Letter for Business Partner

Dear Randy

Will you please consider supporting the International Rett Syndrome Foundation (IRSF) by becoming a Partner (sponsor) of our upcoming fundraiser, the **St. Louis Strollathon** to raise money for Rett Syndrome research? We need your help more now than ever!

The St. Louis Strollathon, set for Saturday, May 3, 2008, is a fun filled, family event, held in Tilles Park. It includes entertainment, food and a beautiful 1-mile stroll through the park.

What is Rett Syndrome?

Rett Syndrome (RTT) is a genetic neurological disorder that occurs almost exclusively in girls. Rett syndrome becomes apparent after 6-18 months of early normal development. It results in a regression that leads to lifelong impairments including loss of speech, purposeful hand use and mobility. It is often misdiagnosed as autism or cerebral palsy and has no cure.

What is IRSF?

The International Rett Syndrome Foundation is the largest and most comprehensive not-for-profit organization for parents, scientists, interested professionals and others concerned with Rett Syndrome. The mission of IRSF is to support and encourage medical research to find a cure and treatments for RTT, to increase public awareness, and to provide information and emotional support for families of children with RTT.

Who's Involved and Affected?

Somewhere in the world, every 5 hours a child is born with Rett Syndrome. RTT affects 1 in 10,000-15,000 live female births. There are over 200,000 girls and women worldwide who have Rett Syndrome.

Several local families and friends have come together to raise critical funding to provide funds for research that will lead to a brighter future for those affected by Rett Syndrome.

Why Now?

Since the discovery of the gene that causes Rett Syndrome and recent research that shows the reversibility of RTT symptoms in mice, we now have an unprecedented and historic opportunity to fund crucial new research. Rett Syndrome is the only autism-spectrum disorder with a known genetic cause. It is often characterized as a "Rosetta Stone", a key that will help unlock treatments and cures for other disorders including autism, schizophrenia, Parkinson's, anxiety and autonomic nervous system disorders.

How Can You Help?

Please look through the enclosed folder which contains the Partner information. You can choose the giving level that best fits your budget and organization. Please be sure to return your forms no later than January 31, 2008 in order to have your logo included on all of our printed materials (T-shirts, brochures, posters, website).

Together, let's help the thousands of beautiful girls who live with the challenges of Rett Syndrome, including our own 8-year old daughter Lilly, have a brighter future. Thank you for your thoughtful consideration and support.

Sincerely,
Joyce, Strollathon Chair and Rett Mom

Sample Letter 2: Letter for Business Partner

Tom:

I am writing to ask that your dental practice consider supporting again this year the event that I am chairing to raise awareness and research funds for Rett syndrome. As you may recall, Rett syndrome is an extremely debilitating autism spectrum disorder that affects females nearly exclusively, and is an affliction that my daughter, Claire, suffers from. The 2nd Annual Fairfax Strollathon is being held at Fairfax Corner on October 21, 2007. The Strollathon will include a walk and family activities, and there will be hundreds of people in attendance.

This past year proved to be an exciting year for anyone who knows or loves a girl affected by the devastating neurological disorder, Rett Syndrome. Remarkable research, funded by the International Rett Syndrome Foundation (IRSF), not only took place, but reached outstanding conclusions! In February 2007, a stunning research announcement revealed that Rett syndrome was *completely reversed* in a mouse model! This experiment proved to scientists that continuing to pursue a cure in humans is a worthwhile endeavor. However, there is much more research to be done and we need your help to fund it. **Will you please consider supporting the International Rett Syndrome Foundation (IRSF) by becoming a sponsor (Partner) of our upcoming fundraiser, the 2nd Annual Fairfax Strollathon to raise money for Rett syndrome research?**

There are promotional benefits for Partners depending on the level of donation. There are a multitude of worthwhile causes and I am very much aware of the many requests we all receive for financial support. However, I can promise you that 95% of every donation will directly fund research -- research that will have ramifications for a broad spectrum of disorders that affect the lives of many of us, including autism, Parkinson's disease, schizophrenia and bipolar disorder.

I have attached a one-page summary of the event, the cause, and the ways in which you could help. I've also attached a Partner Brochure. I would greatly appreciate any support you are able to provide.

Thanks, and I look forward to hearing from you.

Sincerely,

Joanne, Strollathon Chair and Rett Mom

Sample Letter 3 : Letter for your participants to give out

Dear Friends & Family,

On October 21, 2007, I am participating in a Strollathon in Fairfax, VA to benefit the International Rett Syndrome Foundation (IRSF). A Strollathon is a fundraising walk and includes walkers, strollers, and wheelchairs. I ask that you support me in this worthwhile cause.

Rett syndrome is one of the five autism spectrum disorders, and afflicts females almost exclusively. It is the leading cause of severe disabilities in females. I am participating in the Strollathon on behalf of _____, the (daughter/sister) of a (friend/family member/coworker.)

All proceeds from the Strollathon will go to IRSF, a non-profit 501(c)(3) corporation and the world's leading private source of funds for Rett syndrome research. IRSF is dedicated to accelerating treatments and a cure for Rett syndrome. Over 95% of every dollar donated to RSRF directly funds research.

Please consider making a donation (which is 100% tax deductible) to support me. Online donations can be made at www.rettsyndrome.org. Click on the "Strollathon Donate Now" button on the bottom left side of the home page. Please select the Fairfax Strollathon from the Program Area drop down menu and insert (name of child) in the Comments box.

Checks made payable to IRSF can be mailed to:

Insert your name and address

Thank you in advance for your generous support!

Sincerely,
Sign your name

Sample Letter 4: Letter to Potential Donor

Dear Potential Donor,

This letter is a request that you consider participating as an in-kind donor in the **3rd annual News Channel 10 Strollathon for Rett Syndrome** taking place on Sunday, September 16, 2007 in Roanoke, Virginia.

Rett syndrome is a heartbreaking neurological disorder which affects the development of young girls, characterized by repetitive hand movements, irregular breathing patterns, seizures, and loss of speech and motor skills. The International Rett Syndrome Foundation (IRSF) is the largest private source of funds for Rett syndrome in the world. Last year our Roanoke Strollathon raised over \$37,000 for IRSF! In addition, new research, funded in part by IRSF, has **reversed the symptoms** of Rett syndrome in mice, which indicates that there may be a **CURE** on the horizon for these girls! These findings may also help find treatments or even cures for other related disorders such as Autism, Parkinson's and Alzheimer's! IRSF directs **95%** of each dollar donated directly to research, so you can be confident that your donations will go toward supporting a well directed and fiscally responsible foundation.

You can help by donating goods, gift certificates, or other appropriate items for us to use in our Raffle or Silent Auction. Major donors of goods and services will be recognized as Partners in the event.

Please consider this opportunity to contribute to the IRSF and help to find a cure for Rett Syndrome.

Sincerely,

Petrina, Strollathon Chair and Rett Mom

Sample Letter 5: Letter to Potential Captain/Participant

Dear Friend,

The 2007 Ohio-Kentucky-Indiana Strollathon is just seven short weeks away and we're looking forward to another beautiful fall day where tri-state families can come together to roll and stroll for Rett syndrome. We have several new families joining us this year – The Dibble's, the Butler's, the McGuire's, and the Cushman's. We hope you will join these families as we stroll our way to a cure!

With the recent merger of the International Rett Syndrome Association and the Rett Syndrome Research Foundation, we hope to see other new faces (like yours) on September 22. The Strollathon is a wonderful opportunity to meet other families and share experiences.

It's easy to help! Enclosed we have included a collection brochure for you to pass around to your friends and family who want to get involved in raising funds for Rett syndrome. With the formation of the International Rett Syndrome Foundation (our new name) the money you raise will now support our three-pronged program of Research, Family Support, and Advocacy & Awareness – all very important issues for families living with Rett syndrome every day.

Also, keep in mind that it is not too late to put a team together for the Strollathon. Whether your team includes yourself and one other person, or a group of friends and family members is completely up to you. If you would be interested in receiving information and supplies to become a team captain or just need more information in general, please call the IRSF office at 513.874.2657. We hope that you will be able to support our efforts this year and look forward to seeing you September 22 at Sawyer Point!

Sincerely,

Jennifer, Strollathon Chair and Rett Mom

Section 7

Keeping connected

Keeping everyone in the loop is the secret to a smooth-running Strollathon. As Chair, you'll often need to be in touch with your committee, Team Captains and IRSF Administration. In addition to providing coordination, regular communication serves to motivate participants.

You may want to schedule committee meetings every month or six weeks. In between meetings, you need to keep the committee up to date on the Strollathon's progress and the accomplishments of the committee members. The best way to do this is with group emails. Keep them concise and upbeat.

Sample emails:

Sample #1

Hey Gang:

We have our first Platinum Partner! Mary reports that ABC Company has come on board as our first \$1,000 Partner! Way to go, Mary! Keep those Partners coming! And thanks to the rest of you who are hard at work recruiting Partners!

Keep us posted.
Kathy

Sample #2

Hi Everyone:

Just a reminder that the database is set up for our Kickoff Gathering guest list to be entered. Please start emailing you info to Susan. And remember to include zip codes! You don't have to have your whole list done but let's help Susan get started by sending her what we have. We can always keep adding to it!

Thanks and keep up the good work!
Vicki

Sample #3

Dear Committee Members:

Here's a quick update on what others are doing to raise awareness and money for the Strollathon.

Eileen Adams, a special education teacher, sent an e-mail around to all of her teacher friends, asking them to join her team or make a donation. "They all know I work with a girl with Rett syndrome and this cause is so important. I've raised more than \$500 just from that email," she said.

Ariana Martin's family owns a family-style restaurant. She has a picture of her niece, Audrey in the restaurant along with a jar asking for donations. "The money keeps adding up," said Ariana. "And some of our regular customers are signing up for her team."

Sherry Smith is planning a pizza and T-shirt making party for her team. Everyone will gather at her house soon to decorate their team shirts and enjoy some good food!

Brothers Tom and Mike Conrad are each building teams to walk in honor of their cousin's daughter, Christina. The brothers have made a friendly bet as to which team will raise the most money. The losing team has to treat the winning team to ice cream!

Great work, Eileen, Ariana, Sherry, Tom and Mike! All great ideas to help our girls!

Keep up the great work!
Sally

Section 8

Publicity and Promotion

There are several approaches to take to gain publicity and promotion of your event. You will likely have someone on your committee with experience and contacts in this area but if not, a few phone calls is all you need to get the ball rolling.

Any media attention, whether newspaper article, television story or radio announcement, will ideally encourage the public to participate by helping raise money. Request that the coverage provides instructions on how to become involved and a telephone number or email address to use for more information.

Most reporters will ask that you request coverage in writing so use your IRSF letterhead to make such requests. Ask media representatives what their requirements and deadlines are. Begin making requests two to three months prior to the event.

Someone should approach a local TV station proposing a feature piece about Rett syndrome and the Strollathon. A TV station may also consider coming aboard as a Partner so make sure the station manager receives a Partnership Opportunities folder. Many TV stations' parent companies own radio stations too so you may get two outlets (or more) involved. It's not uncommon to bring a TV station on board in a package deal - they'll provide feature, news and calendar listings along with a personality to host your Kickoff Gathering and Strollathon.

Newspapers should also be approached about writing feature articles. Daily newspapers will likely focus on area families and the event itself. Local weekly papers will focus on a family in their readership area. Find out the papers' policies concerning calendar listings and then submit the information.

Keep in mind that pre-event publicity is always beneficial but do not count on additional dollars flowing in as a result of a touching TV news piece or nice article. You're raising awareness about Rett syndrome and the Strollathon and that's important too.

Sample press releases

Pre-event press release

Oct. 1, 2002

Contact: Wendy Thompson, 717-xxx-xxxx

Local families plan Strollathon to help cure Rett syndrome

HARRISBURG - More than 500 men, women and children, along with numerous companies and community leaders, will take a step toward defeating Rett syndrome - a neurological disorder primarily affecting young girls - on Nov. 2 with the first Strollathon for Rett syndrome on City Island.

The walk will raise funds for Rett syndrome under the auspices of the International Rett Syndrome Foundation. There are no treatments or cure for this devastating disease that robs young girls of motor and communication skills. This 1-kilometer pledge walk hopes to bring in more than \$75,000 for the foundation.

Highlights of the event will include appearances by Dennis Owens of ABC Channel 27 News and Autumn Marisa, Miss Pennsylvania 2002. Live music will be provided by BT and the Cruisers. Costumed characters from Hersheypark, as well as clowns, facepainters, train and carousel rides and a city fire engine will also be featured.

Registration begins at noon at the Carousel Pavilion with the Strollathon beginning at 1 p.m. More than 40 teams have registered for this inaugural walk.

Rett Syndrome is a neurodevelopmental disorder which strikes girls usually between the ages of six and 18 months. Previously learned skills such as walking and talking are often lost as is functional use of the hands. Girls with Rett often develop seizures, breathing disorders, digestive dysfunction and scoliosis. Sadly, it is believed that most boys with Rett syndrome die during pregnancy or shortly after birth.

For more information or to participate, call XXXXXX or email strollathon@aol.com

Pre-event calendar listing

BRIDGEPORT - The IRSF Strollathon will be held May 29 at Logan Park. This walkathon will raise much-needed money to support Rett Syndrome research.

Registration begins at 10 a.m. with the walk scheduled for 11 a.m. Prizes, games, pony rides and entertainment will be featured. Several local professional athletes are scheduled to sign autographs.

Also on hand will be several area families living with Rett syndrome, a devastating neurological disorder affecting young girls. Rett robs girls of motor and communication skills. There is no cure.

For more information, call Jill Jones at XXX-XXX-XXXXX www.rettsyndrome.org.

Post-event press release

First Ohio walk raises \$125,000 for Rett syndrome

Contact: Mary Joyce Griffin, xxx-xxx-xxxx

WEST WINDSOR - More than 2,000 Strollers and Rollers weathered rainy conditions to participate in the first Ohio Strollathon for Rett syndrome, held April 23 in Mercer County Park.

More than \$125,000 was collected from participants to benefit the International Rett Syndrome Foundation, according to Mary Joyce Griffin, Chair.

“This Strollathon has exceeded all expectations,” she said. “The success of the walk reflects the widespread interest in finding a cure for so many young girls afflicted with this terrible disease. We are extremely grateful to all our Partners, Team Captains and participants. Their efforts will have a direct impact on moving research forward.”

Major sponsors for the Strollathon include Janssen Pharmaceutical Research Foundation, Johnson & Johnson Consumer Companies, the SmithKline Beecham.

Rett syndrome is a neurodevelopmental disorder which strikes girls usually between the ages of six and 18 months. Previously learned skills such as walking and talking are often lost as is functional use of the hands. Girls with Rett often develop seizures, breathing disorders, digestive dysfunction and scoliosis. Sadly, it is believed that most boys with Rett syndrome die during pregnancy or shortly after birth.

Section 9

Stroll Day

Preparations

The Strollathon will be a fun day for all participants! You'll be able to see all your hard work come to life culminating in a great day for everyone and a substantial amount of money for IRSF. **A party atmosphere is necessary for this family-oriented event. If participants have fun, they will return next year with more of their friends.**

Approximately a month or more before Stroll Day, the Chair(s) and some Committee Members should visit the Stroll site to plan the logistics of the event. Decisions will need to be made concerning the layout of the various tables, signs, etc. that are part of the plan so that as few decisions as possible will have to be made on Strollathon Day.

The major issues to be addressed and planned for include:

- 1) Check-In Area: location and number of tables, number of volunteers, signage requirements.
- 2) T-shirt, Prize area: location and number of tables, number of volunteers, signage requirements.
- 3) Food/Refreshment area(s): location and number of tables, number of volunteers, signage requirements; whether to set up a mid-course refreshment table.
- 4) Stage/Announcement area: location, availability of electric power and Public Address system for this area; what advance arrangements must be made with site officials; what are set-up requirements for morning of Stroll Day?
- 5) Locations for stationary entertainment (e.g. face painting, band or DJ) and required signage, etc.
- 6) Location for team photographs (if a photographer is available and if this is part of your plan for the T-shirt contest); requirements for table, Chairs, etc.
- 7) Location of Start/Finish Line, placement of and method of securing the balloon arch (if you choose to have one), placement of any corporate banners.
- 8) Determination of Starting Line protocol (e.g. countdown, etc.); schedule and content of any pre-start speeches, etc.
- 9) Availability of emergency medical services (ambulance, first aid). Be sure to find out if this is required.
- 10) Availability of/provisions for Security at Check-In area and for post-Strollathon handling of money.
- 11) Parking lot protocol for regular and handicapped parking. Are volunteers necessary? Is signage necessary, and if so, where?
- 12) Availability and location of garbage cans in staging area; protocol for post-Strollathon clean-up. Where to put garbage bags after clean-up? Do recyclables need to be separated?
- 13) Strollathon route. Will signs or markers be needed in order for people to follow the course? Will volunteer route monitors need to be positioned along the course? Are there any danger

points along the course that need to be monitored or roped off (i.e. proximity to water, ledges to fall off, etc.)?

- 14) If volunteers and leaders will be strategically placed, do you need a means of communication? Should walkie-talkies be rented? Should volunteers be asked to bring cell phones, if they have them, and should a listing of everyone's cell phone number be compiled and distributed?
- 15) Availability of toilets, regular and handicap access. Do you need to rent additional portable toilets?
- 16) Plan for bad weather.

When you've nailed down the logistics of your Stroll and Roll, look at it from the perspective of the participant.

He/she arrives at the destination, easily finds parking and then is directed to the registration area. Check-in goes smoothly and then the participant moves on to the party area where there is entertainment, refreshments and prize pick-up.

He/she joins with other team members and poses for the team photograph. Shortly before the start of the Strollathon, a few important people make some inspiring remarks and recognize the Partners and others who contributed to the Strollathon. A countdown is held, the participants participate in the Strollathon and then return to the party area, where entertainment and refreshments are still available. Shortly after the participants return, an estimated total is announced to the crowd.

Volunteer needs

- As detailed below, you will probably want one to two dozen volunteers to participate in set-up, check-in, table-staffing, clean-up, etc. Some of these will need to arrive two to three hours before registration, and others 30 minutes prior to registration. **Virtually all of these volunteers will be able to participate in the actual Strollathon.**
- For set-up of tables, garbage cans, the stage/announcement area and the public address system, at least a dozen volunteers arrive two hours prior to the event and that at least half of these volunteers have the muscle power to move heavy wooden tables and unload boxes of drinks, T-shirts, etc.
- For the check-in process, plan on 4-5 volunteers for each 500 anticipated participants, and these volunteers should arrive 30 minutes before check-in for a brief training session. You will need another volunteer to constantly pick up the check-in envelopes from behind the check-in tables and take them to the accounting table, which should be staffed by one or two volunteers who are proficient with adding machines (calculators or lap top computers) so that running totals of proceeds and numbers of participants can be determined (a preliminary total for each should be announced after the Stroll but before people leave). **It is important to note many donations come in after the event; be certain to explain it is only a preliminary total.**
- For the posting of signs, the number of volunteers needed and the time they should arrive will depend on how many signs you determine are needed and where they should be placed.

(Signs will be needed for the check-in tables, for the special registration table, for the T-shirt and prize tables, for refreshment tables, and for the start/finish Line. Additional signs may be needed for the entrance to the site, for parking, for walking from the parking lots to the check-in areas, for the team photograph area, for various entertainment, and for the Strollathon course itself. Because some of the signs will not be posted until the tables are in place, some or all of the sign posting can be done by the volunteers who have arrived two hours before registration and have set up tables and unloaded refreshments.

- You will probably want to place at least one or two volunteers in each of the parking areas (regular and handicapped) to answer questions and point people in the right direction.
- For the staffing of T-shirt and prize tables, you'll need 2-3 volunteers who would arrive no later than 30 minutes prior to check-in to receive instructions and to lay out the T-shirts and prizes on the tables.
- The numbers of volunteers needed to staff the refreshment tables will be determined based on the variety of refreshments offered and whether a mid-course refreshment table will be set up. At a minimum, there will be one drink table and one food table, each overseen by a volunteer whose job is to keep the tabletop stocked. Most likely you will choose to have about four tables in the main area, and possibly a mid-course table. Therefore, you'll probably need between 2 and 6 volunteers (depending on number of tables), and they should be on-hand 30 minutes prior to registration so that they can stock the tables before people begin to arrive.
- The requirements for clean-up after the event will depend on the site requirements (e.g. will tables have to be returned to their original locations; will garbage have to be carted to a separate area, etc.) At least six volunteers or more, several of them with enough muscle to load up unused refreshments and to move tables, etc., would be needed.

Possible purchases/procurements to be made

Take stock of what food and drink has been promised and whether or not you will need to solicit or procure any additional items. You will need to check with your site contact or your state's Department of Health concerning what types of food can be given to participants.

For signage, you have two options: 1) Use a business that makes signs. The problem with professionally made signs, however, is that they can be very expensive, though they will be well-made. 2) Make your own signs in whatever manner comes to mind. Whichever option you choose, remember that signs should be weather-proof and durable so they can be used year after year.

At check-in, qualifying participants will be given a ticket, sticker, wristband or stamp they can exchange for a T-shirt and a ticket, sticker, wristband or stamp they can exchange for a prize. You must therefore purchase tickets, stickers or wristbands in the number of colors you have prize levels. (For example, if you're awarding T-shirts, baseball caps and umbrellas, you'll need tickets/wristbands in three colors.)

Determine if you'll need to rent any additional tables and chairs.

You may wish to purchase inexpensive plastic tablecloths to put on some or all of the tables (this is probably not necessary but may be a nice added touch). If so, you will also need to devise some method of securing the tablecloths in place so that the wind will not cause havoc (for example, a staple gun could effectively secure the edges of the tablecloths underneath the table).

Determine if you'll need to rent a stage.

Determine if your site has enough bathroom facilities (both regular and handicapped accessible) within a close distance to the Stroll. You may want to ask your site contact if there is a need to rent additional portable toilets.

A public address system (microphone, amplifier and speakers) is essential, and the electricity to run it. Usually, the band or DJ will have an adequate system you can use. If not, you will need to rent a sound system.

You may wish to distinguish your volunteers from the rest of the crowd. You may consider printing some T-shirts of a special color that will be worn by volunteers. This would allow participants to identify volunteers if they need to ask questions. Or, you may wish to make name badges in plastic holders that volunteers can wear. Another option would be to procure volunteer caps.

Each check-in volunteer should have several ballpoint pens (for participants to use in adding missing information to the forms), a stapler and/or rubber bands (depending on which method you choose of securing the check-in envelopes closed), and a supply of extra check-in forms (torn from extra brochures). If possible, it would be a good idea if each check-in table had a calculator available for use by participants who didn't add up the total donations they collected (totals are necessary to determine eligibility for T-shirts and prizes). It is also a good idea for each check-in volunteer to have some envelopes that are pre-addressed with the IRSF address that they can give to participants who have indicated that they have uncollected pledges. Make sure the envelopes are large enough to hold the check-in form and money envelope.

Each of the one or two volunteers at the accounting table should have a portable adding machine with paper tape, and a pad of paper and pencil or pen. Lap top computers can also be used.

If you determine that any areas need to be roped off, you should purchase a roll or two of thin plastic ribbon (similar to what is used to rope off crime scenes). This is available in nice colors (e.g. pink) at office supply and home improvement stores.

Someone should bring tools or supplies necessary for securing signs and other miscellaneous chores:

- hammer
- tape
- rope/string
- removable/self-adhering Velcro patches
- staples
- tacks
- scissors/knives

You need to take inventory of the entertainment you have lined up, and if necessary, procure additional entertainment. Types of entertainment that are typically procured (hopefully on a donation basis, but on a paid basis when necessary) include: face painters, costumed characters, magicians, caricaturists, persons on stilts, clowns, rented or donated transportable games/activities such as moonbounce or ball pit, disc jockey, bands, roving musicians, etc. Having local celebrities like TV/radio personalities and professional athletes sign autographs are also popular. Always a hit are fire trucks on display for the younger set to enjoy. Many fire companies are happy to display a truck and they often distribute goodie bags with safety-themed trinkets.

A fun idea: Have someone on hand from start to finish to videotape (with sound) all aspects of the Strollathon (pre-, during, and post-Stroll) and to interview participants. It's preferable to have access to donated videotaping services, but if not, it is important to identify a volunteer who would do this.

In addition to videotaping the event, it is important to take still photographs. Digital photos might be preferable, because they can more easily be placed on the IRSF website, but film is fine.

Parking

The entrance to the Strollathon site should have a Strollathon banner at it, maybe with balloons attached to attract the attention of the drivers. If there is a possibility that a driver may not know where to go once he/she enters the park, there should be some directional signs or arrows - again with balloons attached - to guide them along to the parking area.

Every site will have different needs as it relates to parking. Work with your site contact person to make sure you know exactly how parking should be handled. If necessary, have volunteers assigned to cover this area.

Give some thought to the route people will take from the parking area to the staging area. You want to make it clear where people are to go once they park. If the main staging area is in clear view of the parking area, this should not be an issue. Having music at the staging area helps make it easy to get the attention of the Strollers and Rollers.

Check-in, money handling

This is the most important part of the Strollathon staging area. It should be clearly marked and the first area that the walkers see as they enter the main staging area. In most cases, checking-in is the first thing a participant does when he or she arrives.

The check-in area should be a long row of 4' by 8' tables with volunteers seated behind them to take the check-in forms and donations envelopes. Some walks organize check-in tables in alphabetical order with about one to four tables for each alpha section. This is an option your committee can decide to use but it is not necessary.

The area behind the volunteers should be inaccessible to everyone but the volunteers. A uniformed security guard or police officer should be stationed here.

The volunteers should each have a calculator, pens, paper, rubber bands or paper clips, and prize “identifiers” such as tickets, stamps or stickers.

The Check-in volunteers verify that the Check-in form is complete and signed. They also check to see if the donations being turned in are totaled. If not, they ask the participant to step aside with the calculator and total their contribution. The volunteer does not remove the checks/cash and verify the total. That will be done later by the IRSF administrative staff.

Once the Check-in form is accepted, the volunteer secures it to the donation envelope with a rubber band or paper clip and places it in a cardboard box behind her/him. Another volunteer periodically collects these from the volunteers’ boxes and takes them to the accounting area.

The Check-In volunteer gives the participant the correct number of tickets, stamps or stickers for prizes, directs them to the prize tables and thanks them for their participation.

The Accounting Area should be staffed with two volunteers who are proficient at using adding machines or laptop computers. They will keep a running total of the donations as the envelopes are brought to them. Again, they will not remove the checks/cash from the envelopes but will simply total the amounts recorded on the outside of the envelopes. By the end of the Strollathon, the accounting volunteers should have a good estimate of the grand total brought in that day and can announce it to the Strollers and Rollers.

Every precaution should be made to keep the money secure. There will be hundreds, probably thousands of checks, plus a large amount of cash (even though we ask everyone to turn in checks). The uniformed police officer or security guard will need to oversee the money-handling at all times until the Strollathon is over and it leaves the site.

Refreshments

The refreshment area should be set up away from the Check-in area so it will draw people away from there after they register. The size of the area depends on the amount of refreshments you have and the number of Strollers and Rollers you expect.

For refreshments, try to stick with pre-packaged, non-perishable snacks whenever possible and bottled water and other drinks like juices, sports drinks and sodas, if desired. Many sites and state Departments of Health will not let you serve perishable food.

Ideally, everything will be self-serve so you will need only a small number of volunteers to staff the refreshment area to keep the stock replenished.

If you expect a warm Stroll Day, ice and containers that can keep drinks cold should be considered. Cool drinks can be offered during the pre-Stroll period but they will be in most demand during and

after the Strollathon. Ice cream and popsicles are also good, especially if a local dairy or vendor can be on hand to serve them.

On the flip side, if you expect a chilly Stroll Day, hot drinks such as coffee, tea, hot chocolate and cider are also good ideas. Try to get a local vendor to serve the drinks. If that's not possible, self-serving vats with hot water or the beverages can be used. Try to borrow them first from restaurants, office snack services, caterers or churches. If none can be borrowed, you can rent them.

Typically, the best snacks to have are:

- granola/breakfast bars
- doughnuts/danishes/bagels
- fruit
- pre-packaged chips/pretzels/crackers (single-serving)
- candy bars
- bottled water
- juice boxes
- sodas
- sports drinks

Video, photos

You'll want to have a good photographer and possibly a videographer on hand. Be sure to appoint 1-2 volunteers for these jobs. Key people should be photographed and interviewed including Chairperson(s), dignitaries, corporate Partners, IRSF representatives. Also important are large teams, committee members and other volunteers and Rett families.

The pictures and/or video will be shown at your following year's Kickoff Gathering. They could also be shown to potential Partners and other organizations considering joining in your next Strollathon.

At the Kickoff Gathering, this video and pictures will be viewed both by returning Strollathon participants and Partners and by newly recruited ones considering participation in the next event. For the veterans, the video and pictures will serve as a pat on the back for a job well done and will be a reminder of the emotional gratification of last year's participation. For the newcomers, it will serve as a sales tool - to establish IRSF as worthy causes and to convey the pleasure and satisfaction of participating in a Strollathon. This video should be about 5-8 minutes in length.

Digital photos are preferable because they can be more easily displayed on the IRSF website, however, film is fine also.

T-shirts, prizes

The T-shirt and other prize tables should be clearly marked but far enough away from the Check-in area so as not to cause congestion. Strollers and Rollers may opt to pick up their prizes before the Stroll but many will also gather theirs afterwards.

Volunteers should have clear instructions beforehand on how to deal with participants who want to bargain or buy prizes.

Keeping the party going

- Generally, the majority of the Strollers and Rollers do not stay around long after the walk. They tend to grab a snack and drink, socialize a little and get on their way. That's why we suggest you make your speeches at the beginning of the event. Of course, at the end, you'll be able to announce your estimated total and again thank everyone for participating.

Here are a few other suggestions for the post-Strollathon activities:

- Have a "Thank You" squad stationed at the finish, thanking and clapping for everyone as they finish. This could be a professional, college, high school or younger cheerleading squad; costumed characters or just a group of enthusiastic volunteers.
- The DJ or band should continue to play music as the walkers complete the Strollathon and for as long as there is a sizable crowd in the staging area. It is always fun when a good DJ can get people up and dancing at the end of the event. Anything he can do to create a festive, fun mood will contribute to the feelings of accomplishment and pride the Strollers and Rollers will be feeling.
- The entertainers and activities should continue after the Strollathon until the crowd really begins to thin out.
- Keep the refreshment tables stocked. If participants can't find a drink and snack that appeals to them, they will likely leave.

Clean-up

Make sure you know your site's requirements for clean-up. Do tables have to be returned to their original position? Does electricity need to be turned off? Does garbage need to be carted somewhere? Does an official need to check over everything before you leave?

Plan to have at least six volunteers scheduled for clean-up, several with enough muscle to move tables and load unused refreshments.

If refreshments are left over and would perish before your next Strollathon, consider donating them to a soup kitchen, food pantry or homeless shelter.

Electricity

Make sure you have access to it if you need it. This may mean extension cords are needed. It may also mean that your staging area needs to be laid out around the availability of power.

Tents

If you are not using a pavilion or some type of sheltered staging area, review your need for tents with your site contact person. Clear your plans with the site person first as many public facilities have restrictions for their use. Tents are expensive to rent so try to get them donated or at a reduced cost first.

First aid

Determine if you'll need a staffed emergency vehicle at your event. And if so, can you get the services donated? Will you have access to a first aid kit?

Section 10

Bookkeeping, Database Entry, Thank You's

The IRSF administrative staff will process the donation checks and cash. Each check is photocopied for IRSF records before it is banked and the names/addresses are entered into IRSF's database. Those persons writing a check will receive a postcard of acknowledgment from IRSF. The staff will keep you informed as to how much money is raised from your Strollathon.

The Chair and committee members will want to write their own thank-you notes to those who made significant contributions to the Strollathon - Partners, media personalities, entertainers, food donors, etc.

Timeline of Key Strollathon-Related Activities

6 to 12 months before event

- Choose date and location
- Secure permits, insurance
- Form Committee
- Compile Kickoff Gathering guest list
- Identify and approach potential Partners

14 weeks before event

- Mail Kickoff Gathering invitations
- Compile database of guests

8 weeks before event

- Hold Kick-off Gathering
- Work closely, keep in contact with Team Captains (now through Stroll Day)
- Prepare press releases and contact media
- Visit Strollathon site to plan logistics
- Begin securing Stroll Day donations (refreshments, entertainment, etc.)
- Compile database of teams, captains, participants

Four to six weeks before event

- Begin weekly emails to Team Captains, noting how many participants are registered on each team and sharing ideas
- Continue updating database

Two to four weeks before event

- Order T-shirts and other prizes
- Pick up donations for event (e.g. water, snacks, etc.)
- Pick up banners from Partners
- Finalize Stroll Day details
- Contact Stroll Day volunteers with details about assignments, times

Within six weeks after event

- Send thank-you notes to those who made significant contributions

Printed Materials

Following is a list of the Strollathon's printed materials, their purpose and estimates of how many of each you'll need to have printed for a first-time Strollathon. The numbers to print will be based on estimates of how many will probably be needed combined with some knowledge of the "break points" in printer cost.

IRSF will work with you to determine your needs. Please read for your information.

The biggest cost of a print job is in the set up; after a certain point, the incremental costs of printing additional copies are significantly smaller. For example, the per unit cost of the first 500 pieces of an item might be 50 cents, but quantities above 500 might cost only 15 cents each. Additional quantities beyond 1,000 might cost only 10 cents. If your realistic estimate of quantity needed is, say 600, you might want to print an extra 150 because the additional cost is significantly less than the cost of reprinting additional pieces later.

The Team Captain folders will contain a Partnership Opportunities brochure, about 10 Collection Brochures, Guidelines for team captains, Guidelines for Letter Writing, an IRSF brochure, an IRSF Research Awards List, and any assorted articles determined relevant by IRSF and the planning committee.

Partnership Opportunities brochures are usually a four-page piece containing the description of the Partnership levels and a confirmation form to be mailed or faxed to the Strollathon committee.

There are two different uses for the Partnership Opportunities brochure. First, the committee will distribute the brochure, along with a cover letter, to all of the potential Partners they will try to solicit. In an early meeting, you may want to take a count from committee members to determine how many brochures to print at first.

Second, these brochures will be placed in the Team Captain folders to be distributed at the Kickoff Gathering. If you are in a position to estimate, at that time, the numbers needed later for the Kickoff Gathering, you can have printed a single, larger quantity at one time. It is likely, however, that the Partnership Opportunities brochure will need to be printed in two batches.

The number of Partnership Opportunity brochures needed for the Kickoff Gathering (as well as for people who cannot attend the luncheon but are interested in participating) will be the same as the number of team captain folders needed. Since many Kickoff Gathering attendees will wait until a week (or less) before the event to RSVP, the printing order must be placed before attendance is known. At previous Strollathon, the initial Kickoff Gatherings were attended by anywhere from 40 to 125 people. The average attendance was in the 50-75 range with another 10-15 people not attending who have expressed an interest in helping out.

You will want to ask each Kickoff Gathering attendee to recruit additional team captains, and for that task you will want to ask attendees to take extra team captain folders with them when they leave the luncheon. Whereas some attendees will take 10 extra team captain folders, others will only take one

or two. If you make up five folders for each anticipated attendee, you will probably have enough left over after the Gathering to send one or two folders to each person who couldn't attend but expressed an interest in participating.

Collection Brochures are usually a five-panel, full-color piece listing the crucial details of the event, the Partners, the registration form, check-in form and sponsor record/envelope. The number needed will be much larger than the number of Team Captain folders. At previous Strollathons, the committee stuffed each Team Captain folder with 10 participant brochures and told Kickoff Gathering attendees to take additional brochures if they anticipated recruiting larger numbers of participants.

Guidelines for Letter-Writing, usually a six-page piece with directions and sample appeal letters to be placed in the Team Captain folders.

Guidelines for Team Captains, usually a six-page piece with directions, team descriptions, and fund-raising tips.

Kickoff Gathering Invitation, with **RSVP postcard** and **envelope**. Print the number of invitations needed as determined by your guest list plus additional ones which can be handed out in mass at PTA meetings, birthday parties, etc.

IRSF brochures, research award lists, and assorted Rett-related and/or IRSF-related articles can be provided by IRSF.

Thank you for your hard work!
It is greatly appreciated!