PARTICIPATION MATTERS

A guide to effectively raise money and awareness for 1p36 Deletion Support & Awareness
Dear 1p36 Deletion Support & Awareness family, friend and supporter:

On behalf of everyone at 1p36 Deletion Support & Awareness (1p36DSA), I would like to extend our sincere thanks for your interest in helping us boost our awareness and fundraising efforts. Whether you have already hosted your own fundraiser or are new to the 1p36 Deletion Support & Awareness community, your active participation means the world to us.

We’ve compiled this guide because it’s critical for all of us to work together within a well-defined set of guidelines. We ask that you carefully review this information (and keep it handy!) as it contains important legal procedures that are necessary to follow when raising money on behalf of 1p36 Deletion Support & Awareness. While we value the wonderful creativity and initiative of our volunteers, our growing organization also needs to ensure that we effectively follow the stringent tax codes established by the IRS with regard to nonprofit fundraising activities.

So once again, thank you. Your participation and your leadership are invaluable to us. Leaders are ordinary people with extraordinary determination. It is because of leaders like you – people who donate their time and money to our cause – that we are able to help individuals affected by chromosome 1p36 abnormalities overcome the obstacles they face to be able to lead healthy, happy and productive lives.

Together, we can continue to make a difference.

Together, we can raise awareness higher than ever before.

Together, we can raise money, which funds our work to provide support and education to families and increase awareness of chromosome 1p36 abnormalities in the public and medical community.

Sincerely,

1p36 DSA Board of Directors

We wish to extend our deepest thanks to the Parent Project Muscular Dystrophy for providing the template for this very useful guide.
1p36 Deletion Support & Awareness Fundraising Events Guide

This section is designed to help you navigate your way as you are planning, executing and wrapping up your fundraiser. 1p36 Deletion Support & Awareness has streamlined this process as much as possible to ensure you receive proper support from us and have a smooth, successful event from beginning to end. You can help by following 1p36 DSA’s C.O.M.P.A.S.S. event guidelines below.

Contact
Organize
Materials
Printing (and publicizing)
Accumulate
Submit
Send “Thank You” Notes
**CONTACT**

Inform 1p36 Deletion Support & Awareness about any event you plan to carry out in its name or under its logo.

**Why this is necessary:**

1p36 Deletion Support & Awareness has an obligation to assure both its Board of Directors and the Federal Government that its activities are compliant with those required of all 501(c)3 nonprofit organizations. Even as a volunteer, the work you do on our behalf “counts.” Each state has its own regulations regarding allowable fundraising activities and its own required registrations. We need to be in compliance in order to maintain our privilege of fundraising across the country.

By providing 1p36 Deletion Support & Awareness with this information in advance, we will be able to assist you as you begin planning your event. If have trouble deciding what type of event to host, give us a call. We will do our best to offer suggestions. Choose the type of event that best reflects your personality, is rewarding for you and one that you have the time and the resources to manage.

Please contact the 1p36 Deletion Support & Awareness Board at info@1p36dsa.org to discuss the fundraising event you have in mind.

**Some basic information you should have ready for 1p36 Deletion Support & Awareness:**

- Name of your event
- What kind of event it is (auction, dinner, golf tournament, etc.)
- Location (City, State)
- Contact name and phone number

**Q:** What should the name of my event be?

**A:** 1p36 Deletion Support & Awareness suggests choosing a name that reflects two things: the kind of event you are having, and 1p36 Deletion Support & Awareness. Some examples are “The Lee Family Golf Tournament for 1p36 Deletion Support & Awareness”, “Race for 1p36 Deletion Support & Awareness” or “Bowlathon for 1p36 Deletion Support & Awareness.” (Names like “Michael’s Challenge” or “Race for Mary” are not as specific and may be confusing to first-time event attendees in regards to what it’s about.)
ORGANIZE

1p36 Deletion Support & Awareness strongly encourages you, the event leader, to organize an event committee.

Why this is necessary:

Events can be overwhelming. Form a committee, or team, to help you plan, coordinate and execute your event. Trying to do an event alone can be hard. It is not to say that this can’t be done, but it certainly adds a lot of pressure on the one person, or one family, to do everything. We suggest gathering a group of family and friends that you can trust and depend on (for deadlines, assistance, honesty, etc.). Sharing responsibilities also makes everyone more invested in the success — and fun — of the event!

Once you have determined who will be on your event committee, organize a kickoff meeting to review the timeline and delegate tasks. By making these decisions early, you help give everyone involved an idea of what you expect from their participation. It will also give you a great guide as you move forward with your event.

Q: Who should I ask to join my event committee?

A: Ideally, you should try to organize your committee with real “go getters.” It takes a certain type of fearless person who is committed to the cause to solicit auction items, sponsorships and donations. It is also wonderful, if possible, to include individuals who have connections with the local business community, the media, local celebrities or local charitable foundations, or anyone who has organized a fundraiser in the past. This is also a great opportunity to involve those family members and friends who always ask, “What can I do to help?” By inviting them to be on your event committee and by assigning them tasks, you empower them to create change in the 1p36 Deletion Syndrome community.

Q: What are the major tasks I should expect?

A: For any public event, you should expect to:

1. Create a timeline
2. Create a budget
3. Find a location
4. Advertise the event
5. Gather the materials and personnel needed for the event
6. Follow-up with thank you’s and accounting for donations and expenses

You will find templates for a number of these activities in the Appendix.
MATERIALS

1p36 Deletion Support & Awareness offers 1p36 Deletion Support & Awareness-produced materials to support your event.

Why this is necessary:

After you’ve called us to discuss your event idea and have an organized plan, please contact us to discuss what 1p36 Deletion Support & Awareness materials might help you promote, publicize, or support your fundraising efforts. We are very happy to discuss the materials we have available and which may be the best fit for your event.

PRINTING (AND PUBLICIZING)

Always use the entire name of our organization: “1p36 Deletion Support & Awareness” and please use “1p36 Deletion Syndrome” as the name of the illness.

There are several names for our syndrome: “1p36 Deletion Syndrome” and “Monosomy 1p36” are the most common. Our best understanding at the time of this writing is that “1p36 Deletion Syndrome” most accurately reflects the nature of the disorder. It also makes the connection with our organization’s name clear.

Before sending out any correspondence – including event invitations or letters – please let us review them for terminology and spelling.

If you plan on creating your own printed materials to use in conjunction with existing 1p36 Deletion Support & Awareness materials, please follow 1p36 Deletion Support & Awareness’s branding guidelines and message points included in the appendix. By following these guidelines and using consistent message points, you effectively raise awareness for 1p36 Deletion Syndrome.

1p36 Deletion Support & Awareness Logo

We will email you a digital version of the 1p36 Deletion Support & Awareness logo if you email your request to info@1p36dsa.org. Any event materials you create which include our logo must be approved by 1p36 Deletion Support & Awareness. Please ensure the 1p36 Deletion Support & Awareness logo on your document looks exactly like the ones online. For instance, it cannot be squished, elongated or use different colors. If it doesn’t mirror the logos online, it is incorrect. Please help 1p36 Deletion Support & Awareness ensure the consistency of our brand. Thank you!
Important:

Before you print your own materials, please e-mail a draft copy of invitations, tickets, programs, press releases etc., to info@1p36dsa.org. We need to review these materials to ensure that they are in compliance with IRS regulations and that they contain accurate information about our organization and the syndrome.

Q: Can I use 1p36 Deletion Support & Awareness letterhead for our solicitation letters?

A: No. 1p36 Deletion Support & Awareness’s policy is to provide each fundraiser with an official letter of support from our organization. We can also work with you to produce a special event letterhead for your fundraiser.

ACCUMULATE

All fundraising events carried out under the 1p36 Deletion Support & Awareness name and logo must adhere to generally accepted accounting procedures (GAAP) for nonprofits.

Why this is necessary:

As we mentioned earlier, 1p36 Deletion Support & Awareness has a legal responsibility to report its income using generally accepted accounting practices (GAAP) for nonprofits. Please follow the guidelines listed below to help us keep track of proceeds from your event.

How to accept donations by check

Please ensure that all checks and donations are made out to: “1p36 Deletion Support & Awareness”. Please make sure the check includes the address of the donor or please write the address on the face of the check.

Make photocopies of all checks and event-related correspondence. When you collect donations and in-kind items for your event, please make photocopies of checks and correspondence for your records and ours. Keeping copies will provide a cross-reference if there are any problems, and will also provide you with a list from which to write personal thank-you notes.

Please bundle your donations together and mail them to 1p36 Deletion Support & Awareness. (See the “submit” section below for more information on how to send us the donations you’ve collected.)

How to take credit card donations

At this time 1p36 Deletion Support and Awareness is not able to take credit card donations directly. If someone wants to donate using a credit card they can do so using a PayPal account or go to www.networkforgood.org and search for 1p36. You can also go to our website at
www.1p36dsa.org and click on the donate button.

**What to do with cash donations**

If you receive cash donations, please go to your local bank and get a bank check (issued to 1p36 Deletion Support & Awareness), or a money order for the total cash amount. Then, mail it to 1p36 Deletion Support & Awareness. Please do not send cash in the mail. It would also be ideal to get the name and address of the person or persons who donated cash.

**Q:** Can I open a bank account, deposit all the donation checks there, and then cut a big check to 1p36 Deletion Support & Awareness?

**A:** No, this does not adhere to generally accepted accounting practices (GAAP) for nonprofits. If you deposit a check made out to 1p36 Deletion Support & Awareness into your bank account, this is considered “co-mingling” funds. Secondly, if your donors make a check payable to you, then they haven’t made a “donation” to 1p36 Deletion Support & Awareness; therefore we cannot provide them with a receipt acknowledging their gift and giving them the opportunity to deduct it from their taxes. Lastly, to open a bank account under the organization’s name is illegal.

**How to record non-monetary items that have been donated, including auction items, food/beverages, etc.**

1p36 Deletion Support & Awareness must have a record of non-cash donations for tax purposes and to acknowledge the donor. For items that are auctioned, we need to know the name and address of the donor and the “fair market value” of the item – how much it would cost to buy retail. We realize that for some items, particularly used items, this will be an approximation. We also need to know how much the item sold and who purchased it. Typically, purchasers do not receive a tax deduction for items purchased at charity auctions unless their winning bid is over the fair market value of the item. They may then deduct the difference between fair market value and the actual purchase price. We send them a tax receipt for this amount.

For non-monetary donations of food or other items that were used at the event, we will need to know the name and address of the donor, the items, and the fair market value of the items. You may use the same form as the one used for auction donations to record this information.

For both auctioned items and donated goods to support an event, we will not list the fair market value of the item on the tax receipt that we send the donor. This figure is for our records only.

We do not need to know about services that are donated as part of the event. For example, if your event includes live music, we do not need to know what the volunteer musicians would charge if they were playing at a for-profit event. Any service that an individual puts into an event is considered volunteer activity and is not tax deductible even if it is in the individual’s line of work.
SUBMIT

Please mail donations, donor information and any additional event correspondence to 1p36 Deletion Support & Awareness within 30 days after your event. The address to send this information is:

1p36 DSA
Care of Karen Bess
48 Cornfield Lave
Warwick, NY 10990

Only send donations in the form of checks, bank check or money order. If someone gives you cash, please send us the person’s name, address, and donation amount if this is available.

If you ask your donors to mail their contribution directly to the 1p36 Deletion Support & Awareness office, please ask them to write your family’s name somewhere on the check so that we can notify you when their donation has been received.

Why this is necessary:

The donor’s information is entered into 1p36 Deletion Support & Awareness’s database with a note that they made a contribution via your fundraiser. Doing this helps us appropriately categorize donations in our database. In turn, we’re able to generate accurate fundraising reports and donor receipts in a timely manner.

The donor’s information is not shared with any other individuals, organizations, or corporations. Some individuals in our database may receive information directly from 1p36 Deletion Support & Awareness in the future, most often our quarterly newsletter.

Your friends may be placed on our newsletter mailing list unless we are told otherwise by you. We believe that donors like to know how their donations are being used, and our quarterly newsletters are full of this information. If we have not received an additional donation from an individual for a period of time, 1p36 Deletion Support & Awareness may remove them from the mailing list. If you believe your donor(s) would not like to receive the newsletter, please let us know and we will not add their names. The donors also have the opportunity to remove their names by emailing or calling us.

Expense Pre-Approval and Reimbursement Forms

1p36 Deletion Support & Awareness recognizes that hosting an event often incurs associated costs. It is our policy to reimburse you for event-related expenses after the event has occurred. After you have formed a budget for your event, please fill out the Expense Pre-Approval form found in Appendix H. The Expense Pre-Approval Form insures expenses are monitored and budgeted appropriately. 1p36 Deletion Support & Awareness will designate, when appropriate, vendors to use to purchase your items and/or services from. This process will guarantee the best
rates and/or prices possible. After the completion of your event please fill out and follow the instructions on the 1p36 DSA Expense Reimbursement Form. All expenses must be submitted with corresponding receipts and the expense reimbursement form you will find in Appendix I.

Please keep your fundraising costs to a minimum. When at all possible, try to get donations of the goods you need or ask for a percentage discount. Many stores are willing to help out a good cause. If you need help, just let us know.

SEND THANK YOU NOTES

1p36 Deletion Support & Awareness believes in the importance of donor integrity and is committed to acknowledging the generosity of all 1p36 Deletion Support & Awareness donors.

Why this is necessary:

One phrase commonly used in the nonprofit sector is “thank before you bank.” This phrase simply underscores the importance of sending tax receipts and thank-you letters in a timely fashion after an event.

All tax receipts must be issued from the 1p36 Deletion Support & Awareness treasurer in order to comply with Federal Law. However, we also encourage you, the fundraising host, to send a personal “thank you.” In your note, you may want to include a sentence that states, “Keep an eye out for your official tax receipt in the mail from 1p36 Deletion Support & Awareness.”

Q: How soon will donors receive their “thank you” letter and tax receipt from 1p36 Deletion Support & Awareness?

A: Once donations are received in the 1p36 Deletion Support & Awareness’s office, we input each check and issue “thank you” letters and tax receipts. This process usually takes anywhere from 2-4 weeks, depending on the time of year and volume of donors.
Media Relations Roadmap

Hosting a 1p36 Deletion Support & Awareness fundraising event in your community is a terrific opportunity to garner media attention. The effective use of free media opportunities gives you the chance to raise awareness about 1p36 Deletion Syndrome among your community and to call attention to the importance of raising funds.

You don’t have to be a seasoned public relations professional or publicist to capture the attention of editors and reporters. However, you have a better chance of getting your event covered by many with some proven methods of generating media interest. It often takes lots of friendly follow up and persistence to break through the clutter in a newsroom. Your biggest strength is your passion and enthusiasm for — and accurate knowledge of — the importance of raising 1p36 Deletion Syndrome awareness dollars.

Tools to help you get press:

To make it easier for you, 1p36 Deletion Support & Awareness has put together some tips on how best to catch an editor’s ear and communicate messages about 1p36 Deletion Support & Awareness and 1p36 Deletion Syndrome. On the following pages, you’ll find:
• Tips for pitching the media
• Key talking points on 1p36 Deletion Support & Awareness and 1p36 Deletion Syndrome
• A “swiss cheese” pitch letter and press release (you fill in the blanks!)
• General interview tips

Confidentiality and Sensitivity Issues

1p36 Deletion Support & Awareness is sensitive to the fact that discussing 1p36 Deletion Syndrome can bring up sensitive issues for you and your family. We understand if there are parts of these press materials that you would like to edit in order to keep you and your family comfortable. Talking about 1p36 Deletion Syndrome can be difficult, but we also encourage you to ‘go for it’ because of how important it is to increase awareness of this syndrome.

Research: know your local reporters and their beats

As with any form of communications, know your audience. Before you send a pitch letter, press release or pick up the phone, compile an accurate media list. Find the names of editors and reporters who report on related topics, such as community-, health- or science-related topics. In other words, find out their beat. And you can often find their contact information (phone, fax, email) and instructions for submitting a story idea online or in a hard copy of the publication.
Here are some reporters most likely to cover your story:

**Daily newspapers** – Features Editor, Calendar Editor, Health Reporter, Metro Desk  
**Weekly newspapers** – Features Editor, Calendar Editor, Health Reporter, Metro Desk  
**Television stations** – Assignment Desk, News Desk or Health Reporter  
**Radio news stations** – News Desk

**Pitch: tell your story**

A “pitch” is used to make an editor or a reporter sit up and take interest in your story. It can take the form of a one-page letter (see appendix) or a phone call. The two most important things to remember: keep it brief (it’s a teaser) and give them a compelling reason why they should cover your story. For instance, why would your event or your personal story be of interest to their readers? Why are you hosting a fundraising event? At the end of the letter or conversation, offer to send them more information in the form of a press release (see appendix).

**Tips for talking about 1p36 Deletion Syndrome**

With its complex nature and extensive scientific terminology, 1p36 Deletion Syndrome can be difficult to understand fully. We’ve compiled our recommendations below to help you better communicate about 1p36 Deletion Syndrome with reporters, event attendees and other parents.

<table>
<thead>
<tr>
<th>Negative adjectives and phrases to avoid</th>
<th>Positive adjectives and phrases to use</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>Suffers from</em></td>
<td><em>Diagnosed with</em></td>
</tr>
<tr>
<td><em>Terrible, debilitating syndrome</em></td>
<td><em>Chromosome abnormality</em></td>
</tr>
<tr>
<td><em>Afflicted with</em></td>
<td><em>Affected by</em></td>
</tr>
<tr>
<td><em>Disease</em></td>
<td><em>Genetic Disorder/Condition</em></td>
</tr>
</tbody>
</table>

Words like ‘normal’, ‘fulfilled’ and ‘productive’ should be used carefully so the sentence does not imply that those affected by 1p36 Deletion Syndrome aren’t ‘normal’, ‘fulfilled’ or ‘productive’.

**About 1p36 Deletion Support and Awareness**

1p36 Deletion Support & Awareness (1p36 DSA) was founded in 2009 by parents of children diagnosed with 1p36 Deletion Syndrome in hopes to bring support to families and greater awareness to society regarding this condition. 1p36 Deletion Syndrome is a very rare genetic condition that researchers are still learning about. In fact, it often goes undiagnosed, making planning and care needlessly difficult. Some characteristics of 1p36 Deletion Syndrome include hypotonia (low muscle tone), hearing loss, seizures, heart defects and intellectual disability. Often when a child is diagnosed with 1p36 deletion syndrome, parents, and even medical professionals, are at a loss for information regarding this syndrome. Recognizing the need for
connection and networking, many dedicated parents have worked on their own to bring 1p36 families together and to raise awareness regarding this condition. Through Internet message boards, personal websites, blogs and eventually conferences, families were finally able to connect and share information with each other and with medical professionals.

Initially conceived in the fall of 2008 and officially incorporated on March 9th, 2009, 1p36 Deletion Support & Awareness grew out of those previous efforts by individual 1p36 parents. The organization currently consists of a five member volunteer Board of Directors comprised entirely of parents of children with 1p36 Deletion Syndrome. 1p36 DSA received 501(c)3 non-profit status on November 22nd, 2009. This means 1p36 DSA is officially recognized as a federal non-profit organization. This status will help 1p36 DSA gain the funding needed to accomplish its specific goals as outlined in its strategic plan.

Through a collaborative effort involving the Board and the 1p36 parent community, a mission statement was adopted. The mission statement states 1p36 DSA’s main overall goals and identifies the individuals the organization serves.

Our mission is to help individuals affected by chromosome 1p36 abnormalities overcome the obstacles they face to be able to lead healthy, happy and productive lives. We do this by providing support and education to their families and increasing awareness of chromosome 1p36 abnormalities in the public and medical community.

1p36 DSA is governed by the needs of the community of 1p36 families. It exists to bring a brighter future to all individuals with 1p36 Deletion Syndrome. Mutual respect, cooperation, honesty, inclusiveness, integrity and responsibility make up the values that 1p36 DSA will always adhere to in all its practices.

When you talk about 1p36 Deletion Syndrome to a reporter, here are few things to keep in mind:

Be prepared.

• Know the five “Ws” of your event: who, what, when, where, why (and how).
• Be familiar with a publication and its audience.
• Have 1p36 Deletion Support & Awareness’s mission statement and key messages with you for reference.

Be truthful and direct.

• Make your key points as simply and as often as possible.
• Have engaging examples or anecdotes to back up your key points. Tell your personal story.
• If you don’t know the answer to a reporter’s question, admit it and offer to get the information for the reporter as soon as possible. (Be sure to follow up!)

Be confident and relaxed.
• You are the expert.
• A successful interview is often a conversation, not an inquisition.

Be sure you understand the question before you answer.

• If you’re not sure what the reporter is asking, say so.
• It’s OK to ask a reporter to back up or rephrase a question.

Be aware of saying things “off the record”

• It doesn’t exist; what you say can be quoted.
• Never say “no comment.”
• Give a reason for why you can’t discuss certain topics or issues.
• There are many ways to give a “non-answer” answer. You can redirect the conversation by saying, “I can’t discuss that, but what I can tell you is that our program is successful because…”

Don’t be afraid to show emotion.

• This is a very emotional topic for you and your family…and for many other families out there who may really connect with your message and be inspired by your story. Silences, or long pauses, are OK.
• When you’ve made your point, stop speaking. Don’t feel like you have to keep talking. People often speak nervously to fill the silence, which may dilute their original, well-articulated point.

Remember, you have control over what you say in an interview.

• The editor has ultimate control over what finally appears in print or on the air.

Press Release:

1p36 Deletion Support & Awareness has written a “swiss cheese” Event Press Release (see appendix). It contains key points and messages and leaves “holes” for you to fill in and distribute to the media. It’s suitable for all types and sizes of events - from letter writing campaigns, to change drives, to bake sales, to dinner dances. Any and every event counts and we want as many people as possible to know about it.

After you’ve personalized your press release, you’re ready to send it via fax or email to the contacts on your media list. Be mindful of publications’ deadlines. In some instances, they need to be notified six weeks before the event in order to be included in the calendar listing.

Follow up: be friendly, yet persistent
After you distribute your press release to your media list, be sure follow up. Editors and reporters are typically under deadline and have a lot going on, so give them a few days to get to it. Then pursue your first-round of follow up with a call or email. We suggest that you ask if they received the release OK, gauge their interest in covering your story and stress that you’re available to help.

Don’t be discouraged if it takes you several attempts to reach an editor or reporter. Following up, whether it’s the first-round or third-round, is a great opportunity to stay in the reporter’s mind and build a relationship. Sometimes just a friendly, informative 30-second conversation can go a long way.

**Press Placement**

1p36 Deletion Support & Awareness would appreciate receiving a copy of all press placements you receive, so we can keep our media records as accurate and up-to-date as possible.

**Final Outcome**

Please do not to be discouraged if your press releases and story ideas do not get placed. For whatever reason, many press releases slip by the wayside and never make it to print. Your efforts are still worth it, and we appreciate all the time you’ve spent.
Appendices

Appendix A  --1p36 Deletion Support & Awareness Key Messages
Appendix B  --Pitch Letter to the Editor
Appendix C  --Press Release
Appendix D  --Auction Item Solicitation
Appendix E  --Auction Budget Worksheet
Appendix F  --Sample Benefit Auction Timeline for Live/Silent Auction
Appendix G  --Gift in Kind Tracking Form
Appendix H  --Expense Pre-Approval Form
Appendix I  --Expense Reimbursement Form
Appendix A
1p36 Deletion Support & Awareness Key Messages

About 1p36 Deletion Syndrome:

• 1p36 Deletion Syndrome is a congenital genetic disorder caused by the deletion of the most distal light band of the short arm of chromosome 1. Chromosome 1 is the largest human chromosome and represents about 8 percent of the total DNA in human cells. The "p" stands for the short or 'petite' arm of the chromosome. “36” stands for the location of the deletion on the chromosome.

• 1p36 Deletion Syndrome is one of the most common deletion syndromes. It is estimated that the syndrome occurs in one in every 5,000 to 10,000 births.

• 1p36 Deletion Syndrome is characterized by moderate to severe intellectual disability, delayed growth, hypotonia, seizures, limited speech ability, malformations, hearing and vision impairment, and distinct facial features. The symptoms may vary, depending on the exact location of the chromosomal deletion.

• Those diagnosed with 1p36 Deletion Syndrome respond well to a variety of different therapies. These include speech, physical, and occupational as well as many others. Early diagnosis and intervention is very important.

• 1p36 Deletion Syndrome is a result of a random spontaneous genetic mutation that can occur during any pregnancy regardless of family history. In a few rare cases it can be handed down from the parents.

The greatest challenges that our fundraiser will help 1p36 Deletion Support & Awareness to address:

• Families with loved ones with 1p36 Deletion Syndrome often feel isolated because they do not know anyone else with the illness. 1p36 Deletion Support & Awareness provides many opportunities for individuals and families to have contact with others who are in a similar situation. They also distribute information about the illness so that patients can make informed decisions about their loved ones care.

• Physicians, including pediatricians, are not familiar with the disorder. 1p36 Deletion Support & Awareness has been working to create physician education materials and to educate more of those in the medical community to be aware of 1p36 Deletion syndrome.
Appendix B
Pitch Letter to the Editor

Editor or Reporter’s Name
Newspaper or other publication
Address (City, State, Zip)

[Date]

Dear [Editor or Reporter’s Name]:

I am writing to suggest a story idea to raise awareness about a devastating, little known disorder that affects 1 in 5000 births in the United States – including our [son/daughter/friend, etc – we’ll use son in this example].

Despite its prevalence, not much is known about 1p36 Deletion syndrome in our own neighborhoods and communities. 1p36 Deletion Syndrome is a congenital genetic disorder caused by the deletion of the most distal light band of the short arm of chromosome 1. Chromosome 1 is the largest human chromosome and represents about 8 percent of the total DNA in human cells. The "p" stands for the short or 'petite' arm of the chromosome. “36” stands for the location of the deletion on the chromosome. To date, there is no cure. Our [son], [your son’s name], was diagnosed with 1p36 Deletion Syndrome in [year], and we’ve become active members of a nonprofit organization called 1p36 Deletion Support & Awareness.

On [date of event], we are hosting a [type of event] to raise awareness of 1p36 Deletion Syndrome and raise funds for 1p36 Deletion Support & Awareness. The organization’s mission is to help individuals affected by chromosome 1p36 abnormalities overcome the obstacles they face to be able to lead healthy, happy and productive lives. We do this by providing support and education to their families and increasing awareness of chromosome 1p36 abnormalities in the public and medical community.

We ask that you consider covering our event. You could help your readers gain invaluable information about 1p36 Deletion Syndrome, which can affect any family in our community. You’d also be giving your readers a great way to support our efforts on behalf of 1p36 Deletion Support & Awareness.

Sincerely,

[Your name]

[Your phone number] [Your email]

P.S. A press release is available upon request.
Appendix C
Press Release

For Immediate Release: [Date]
Contact: [Your name, Phone, Email]

LOCAL FAMILY FIGHTS FOR A CAUSE CLOSE TO THEIR HEART AND HOME
[Your hometown] Family Hosts a [Type of event] to Raise Awareness and Funds for 1p36 Deletion Syndrome.

(HOMETOWN, STATE) – [Your affected person’s full name] is a fighter. (For instance, five-year-old Brandon Smith is a fighter.) And the name of his toughest opponent is 1p36 Deletion Syndrome. When [affected person] was [your affected person’s age of diagnosis], he was diagnosed with 1p36 Deletion Syndrome. 1p36 Deletion Syndrome is a genetic disorder caused by the deletion of the most distal light band of the short arm of chromosome 1. However, with the spirit of any good fighter, [he] lives life to the fullest, surrounded by the love and support of [his] family and community.

On [event date], [your affected person’s name] family and friends will host a [type of event] at [event location] to raise awareness of 1p36 Deletion Syndrome, a little known and often misunderstood disorder, and to raise funds on behalf of 1p36 Deletion Support & Awareness. 1p36 Deletion Support & Awareness is a national nonprofit organization started in 2009 by a group of families just like ours that wanted to help make a difference in the lives of those affected by 1p36 Deletion Syndrome. The [your family’s name] family is actively involved with 1p36 Deletion Support & Awareness and hopes to inspire the [your city/town’s name] community to come out, have fun and make a generous contribution in support of [your affected person’s name] and 1p36 Deletion Support & Awareness.

(Use this or draft a similar quote) “We want everyone to know more about 1p36 Deletion Syndrome and how it affects people in our own neighborhoods and communities,” said [your full name]. “Our [type of event] is a fun way to raise awareness; however, the purpose of the event is very serious because much more research is needed to fight this disorder.”

About 1p36 Deletion Support & Awareness
1p36 Deletion Support & Awareness is a non-profit organization founded in 2009. The mission of 1p36 Deletion Support & Awareness is to help individuals affected by chromosome 1p36 abnormalities overcome the obstacles they face to be able to lead healthy, happy and productive lives. We do this by providing support and education to their families and increasing awareness of chromosome 1p36 abnormalities in the public and medical community. 1p36 Deletion Support & Awareness is the only organization in the US focused entirely on support and education for 1p36 Deletion Syndrome. For more information, visit www.1p36DSA.org
Interviews Available

The [Your family’s name] family, and 1p36 Deletion Support & Awareness Board of Directors are available for interviews.

Event listing details:

Who: (your family name & any other community partners)

What: (name of event)

Where: (address, intersection, location and directions, if needed)

When: (day, month, date, year, time frame)

Why: To raise awareness and money for 1p36 Deletion Syndrome on behalf of 1p36 Deletion Support & Awareness

Additional Info (ticket cost, entertainment, etc.)
Appendix D
Auction Item Solicitation

Contact’s Name
Company Name
Address (City, State, Zip)

[Date]

Dear [Contact’s Name]:

The [your family’s name] family, in collaboration with 1p36 Deletion Support & Awareness, will hold a benefit dinner and auction to support 1p36 Deletion Syndrome support and education.

In [year of diagnosis] our son, [son’s name], was diagnosed with 1p36 Deletion Syndrome. 1p36 Deletion Syndrome is a congenital genetic disorder caused by the deletion of the most distal light band of the short arm of chromosome 1. Chromosome 1 is the largest human chromosome and represents about 8 percent of the total DNA in human cells. The "p" stands for the short or 'petite' arm of the chromosome. “36” stands for the location of the deletion on the chromosome. It is estimated that 1p36 Deletion Syndrome occurs 1 in every 5,000 to 10,000 births.

1p36 Deletion Support & Awareness was founded in 2009 by parents of children diagnosed with 1p36 Deletion Syndrome in hopes to bring support to families and greater awareness to society regarding this condition. The mission of 1p36 Deletion Support & Awareness is to help individuals affected by chromosome 1p36 abnormalities overcome the obstacles they face to be able to lead healthy, happy and productive lives. We do this by providing support and education to their families and increasing awareness of chromosome 1p36 abnormalities in the public and medical community. 1p36 Deletion Support & Awareness is the only organization in the US focused entirely on support and education for 1p36 Deletion Syndrome. The organization works closely with patients, families, researchers, and physicians. For more information, visit http://www.1p36dsa.org.

Our benefit dinner and auction will be held at [location of event with address] on [date]. We expect over [estimated number] people to attend and bid on auction items. Will you support our fight against 1p36 Deletion Syndrome? We invite you to participate in one or more of the following ways:

- Donate auction items (goods or services).
- Make a cash donation (to be used towards the purchase of needed items for the dinner or auction).
- Attend the dinner auction.
If you are interested, please send your cash donation or auction items to [name and address]. We would like to receive all gifts by [date]. We are also happy to arrange pick-up of any item. Please keep in mind: your gift is tax deductible. You will receive a letter and receipt from 1p36 Deletion Support & Awareness to be used for tax purposes.

Thank you for considering our request. Feel free to call me at [###-###-####] with any questions. Together we can both benefit. You/your company will receive recognition at the auction and 1p36 Deletion Support & Awareness will be able to make more people aware of 1p36 Deletion Syndrome.

Sincerely,

[Your name]
## Appendix E
### Sample Auction Budget Form

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<td>_____ @ $_____</td>
<td>$_________</td>
</tr>
<tr>
<td>Silent Auction</td>
<td></td>
<td>$_________</td>
</tr>
<tr>
<td>Live Auction</td>
<td></td>
<td>$_________</td>
</tr>
<tr>
<td>Total Income</td>
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<td>$_________</td>
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<table>
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<th>Expenses</th>
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</thead>
<tbody>
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<td>Food</td>
<td>$_________</td>
<td></td>
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<tr>
<td>Beverages</td>
<td>$_________</td>
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<tr>
<td>Invitations</td>
<td>$_________</td>
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<td>Postage</td>
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<td>$_________</td>
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<td>Decorations</td>
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<td>Advertising/Promotions</td>
<td>$_________</td>
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<td>Insurance</td>
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<td>Liquor License (if needed)</td>
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<tr>
<td>Miscellaneous</td>
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</tr>
<tr>
<td>Total Expenses</td>
<td></td>
<td>$_________</td>
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</tbody>
</table>

Net Revenue $_________
Appendix F

Sample Auction Timeline
(This timeline can be modified for use with any fundraiser)

12-14 weeks before the auction

- Assemble committee and co-chairs
- Find and confirm location for event (or earlier if possible)
- Assign subcommittee responsibilities in the following areas:
  - Securing auction items
  - Auction operations
  - Food and refreshments
  - Invitations and promotion

10-12 weeks before the auction

- Send letters soliciting auction items

8-10 weeks before the auction

- Write and design auction invitation
- Do follow-up calls for auction items
- Secure services of auctioneer
- Solicit donated food and refreshments or meet with caterer
- Begin compiling invitation list

6-8 week before the auction

- Begin writing auction program (Assign smaller auction items for silent auction; bigger items for the live auction, usually no more than 10 or 12 items for the live auction.)
- Send invitation to printer
- Recruit volunteers for following jobs:
  - To check-in guests on the night of auction
  - To set up auction tables, decorate, and arrange auction item
  - To act as bid spotters for the live auction
  - To prepare food if not catered
  - To take payments after the auction
  - To clean up after event

4-5 weeks before the auction
• Recruit volunteers to address and mail invitations
• Finalize auction program to include with invitation
• Mail media releases to local news outlets

3-4 weeks before the auction

• Address and mail invitations with program
• Make follow-up calls to potential donors of food and wine if you’re seeking them
• Tour auction location and note any special requirements or potential problems
• Submit to 1p36 DSA Expense Pre-Approval Form

1-2 weeks before the auction

• Prepare bidder’s cards (assign each guest a number for use to record bids)
• Prepare silent auction bid sheets (assign a minimum bid for each item)
• Confirm auctioneer
• Confirm volunteers to work on day of event

1 week before auction

• Visit venue to make final arrangements for decorating
• Purchase decorations
• Create attendance lists for check-in table
• Arrange for drop off of auction items

Day of event

• Decorate venue
• Set up auction tables with silent auction items and bid sheets
• Set up refreshment/drink tables
• Set up check-in tables
• Be sure volunteers are in place and understand the tasks assigned

Final checklist and tips

• Ask auctioneer or MC to encourage bidding on silent auction items
• Set a firm time for closing silent auction bids and announce the time remaining at five minute intervals
• Be prepared at end of auction for buyers who will want to pay and receive their items all at the same time.
### Appendix G

**Gift In Kind Tracking Form**

Event Coordinator Name: _____________________________________________________________

Type of Event: _____________________________________________________________________

Date of Event: _______________  Location of Event: _________________________________

<table>
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<th>Donor Name</th>
<th>Donor Street Address</th>
<th>Donor City/ST/Zip</th>
<th>Item Donated</th>
<th>Fair Market Value</th>
<th>Purchaser (if applicable)</th>
<th>Purchase Price</th>
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</thead>
<tbody>
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<td>Donor Name</td>
<td>Donor Street Address</td>
<td>Donor City/ST/Zip</td>
<td>Item Donated</td>
<td>Fair Market Value</td>
<td>Purchaser (if applicable)</td>
<td>Purchase Price</td>
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Appendix H

1P36 Deletion Support & Awareness
Expense Pre-Approval Form

Before spending any money on behalf of 1p36 Deletion Support & Awareness, please complete the below Expense Pre-Approval Form. The Expense Pre-Approval Form insures expenses are monitored and budgeted appropriately. 1p36 Deletion Support & Awareness will designate, when appropriate, vendors to use to purchase your items and/or services from. This process will guarantee the best rates and/or prices possible. The Expense Pre-Approval Form is approved by the Board of Directors and signed by the Treasurer. This form must be sent to the 1p36 Deletion Support & Awareness Treasurer 14 days before the date of requested purchase.

Note: No actual reimbursement can be made without completing the Expense Reimbursement Form and having actual receipts or other sufficient documentation. See Expense Reimbursement Form for more details.

EXPENSE PRE-APPROVAL PROCEDURE

1. All requests to purchase shall be submitted on the 1p36 Deletion Support & Awareness Expense Pre-Approval Form. PLEASE PRINT CLEARLY.
2. A separate Expense Pre-Approval Form must be completed and submitted for each Fundraiser and/or Event.
3. Expense Name, Description and Approximate costs must be included.
4. Email the completed Expense Pre-Approval Form to info@1p36dsa.org
5. Please keep a copy for your records.
6. You will be notified by email with 14 days of 1p36 DSA’s receipt of the form if expense pre-approval is granted. Incomplete forms will delay processing.

EXPENSE PRE-APPROVAL REQUEST FORM

General Information:

Date of Request: __ / __ / _____

Fundraiser or Event Description: ____________________________________________

Date of Fundraiser or Event: __ / __ / _____

Total Amount of Request: $________________________________________________
Request Submitted By:

Name: ________________________________________________________________

Mailing Address: ______________________________________________________________________________________

City: _______________________ State: ________________ Zip: __________

Email Address: ___________________________ Phone Number: ___________________

Requested Purchases:

<table>
<thead>
<tr>
<th>Name</th>
<th>Description</th>
<th>Approximate Cost</th>
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1p36 Deletion Support & Awareness Treasurer’s Use Only:

Date Received by Treasurer: __ / __ / _____

Approved by Board of Directors:  __ YES __  NO    Date:  __ / __ / _____

Treasurer’s Signature: ________________________________

Comments: 
Appendix I

1P36 Deletion Support & Awareness
Expense Reimbursement Procedure & Form

To receive reimbursement for amounts you spend on behalf of 1p36 Deletion Support & Awareness, please complete the Expense Reimbursement Form and attach all original receipts. No reimbursement can be made without actual receipts or other sufficient documentation. **Please submit a separate reimbursement form for each person or company requiring reimbursement.** This form must be mailed to the 1p36 Deletion Support & Awareness Treasurer within 30 days after the fundraiser or event.

**REIMBURSEMENT PROCEDURE**

1. All expenses for reimbursement must be pre-approved by the Treasurer (*See Expense Pre-Approval Procedure & Form*).
2. All expenses for reimbursement shall be submitted on the 1p36 DSA Expense Reimbursement Forms. **PLEASE PRINT CLEARLY.**
3. A separate reimbursement form must be completed for each person and/or company requiring reimbursement.
4. Original receipts are required as documentation and must be attached to the form.
5. Forward the completed form and receipts to:
   1p36 Deletion Support & Awareness
   Attn: Karen Bess
   48 Cornfield Lane
   Warwick, NY 10990
6. Keep a copy for your records
7. Reimbursement checks will be issued within 14 days of receipt of Form unless further clarification is needed. Incomplete forms will delay processing. Request for status can be emailed to info@1p36dsa.org

**REIMBURSEMENT FORM**

**General Information:**

Date of Request: ___ / ___ / ______

Expense Description: ________________________________________________________________

Total Amount of Reimbursement: $___________________________________________________

Name of Person Submitting Form: __________________________________________________
Make Check Payable to:

Name or Company:________________________________________________________

Mailing Address: ______________________________________________________________________

City: _______________________ State: ____________ Zip: ____________

E-mail Address: ______________________________________________________________________

Phone Number: ______________________________________________________________________

<table>
<thead>
<tr>
<th>Description of Expense</th>
<th>Date</th>
<th>Amount</th>
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</tbody>
</table>

Total to be Reimbursed

1p36 Deletion Support & Awareness Treasurer’s Use Only:

Date Received by Treasurer: __ / __ / ____ All Receipts or Documentation Attached? ___ YES ___ NO

Approved? ___ YES ___ NO  Date Reimbursed: __ / __ / ____  Amount Reimbursed: $_____

Treasurer’s Signature: ________________________________  Check Number: ________________