

## **Dandy-Walker Alliance**



## **Walk/Run Guide**

Thank you for your interest in having a Walk/Run fundraiser in your community. We want to help your event be as successful as possible. This guide has been prepared based on our experience in planning a Walk/Run Fundraiser. It is only a guide, you may choose to have a bigger or smaller event, and whatever you feel will work best in your community! Use your imagination, have fun and educate your area about Dandy-Walker Syndrome!

## How it works

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Walk/Runs have been the fundraiser of choice for many organizations over the years, if you've never attended one the concept is simple. It starts with you picking a day and location to hold your event. Prior to the event you meet with several organizations in your community to invite them to participate. Anyone interested in participating is given a mail out packet which consists of at least 15 letters that they send out to family and friends around the country requesting sponsorship in the Walk/Run. The sponsors of each participant mail their donation, along with the filled out sponsor sheet, back to a predestinated person who keeps track of the participants, their sponsors and donations. The day of the event your participants walk, your guests have a fun filled day and at the end of it all you can give awards like certificates or trophies to the participant(s) who walked the most and/or raised the most money!

## Planning

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1. At least two months prior to the event establish an event committee. This should ideally be a core group, to begin with, of 5 people so that no one is overworked. If you have ever done any kind of event before, you realize that this is the ideal and that each key person would have two or three additional people they can rely on. Do the best you can to delegate so you don't over tax anyone. You will need:

- One person in charge over all. This person carries the check-list and makes sure everyone else is communicating with each other.
- A person with very good bookkeeping skills to track donations and donor mailing/contact information. (We can send you samples of how we've done it in the past.) This person should have the ability to devote some time each day from the time the first mail out goes out until two or three weeks after the event.
- One person in charge of advertising and talking to groups of potential participants.
- One person in charge of "details" that will arise unexpectedly.
- One person in charge of distributing mail outs to locations when needed.

*While one person can pull an event off by themselves you'll have a lot more fun if you can get a few friends or family members to help. The memories you'll make and the stories you will look back on will last a lifetime.*

2. Determine a date for the event. Be sure to consult as many local calendars of events as you can so there is the least amount of conflict. There will always be something, but choose the best date you can. If you choose to do the event outdoors, pick a rain date.

3. Establish a participant base—school groups, civic groups, fraternal groups, church groups and/or community based. These should be a group of people that you can count on to send out mailers for sponsorship and to give you connections to other groups that you can speak to for participation. Each participant is asked to mail out at least 15 sponsorship flyers to people they know. Encourage them highly to mail these to people out of town—it spreads awareness of DW and you will not drain your base of local people. Please let them know that they can send out more than 15 if they like. We've found that people who send out 30 mailing will generate about \$500 in donations. If they need more sponsorship flyers you can provide extras or they can photo copy one.

4. Determine one mailing address (perhaps the bookkeeper) to receive sponsorship flyers as they are returned with donations and pledges.

5. Make a list of businesses that you or a member of your event committee can contact for a corporate sponsorship of \$100-\$250-\$500. Smaller businesses will many times support you for \$250, if you have the opportunity to contact a large business, don't hesitate to ask for the \$500 or more. Also be sure that any employees who participate from employers making corporate donations ask about matching donations.

6. Make a list of organizations, in addition to your base, that you or a representative can speak to about Dandy-Walker (Note: See picture of presentation board and CD presentation; these are great tools but you can also generate something of your own. ) Take pictures of kids in your community who have DW or hydrocephalus to make this personal to your community. If you can, take a parent of a DW child with you. Anything you can do to immediately tie this event to your community is of benefit.

7. Nail down a location. We highly recommend a school or community building with a large gym or, ideally, a gym with a connecting cafeteria/stage area. We learned by experience that the indoor venue takes a lot of strain off the event. (1) You can typically set up much of the event the night before (2) you do not have to worry about the weather (3) power for microphones, speakers, etc. is a non-issue when you are indoors. Check with your location about any special considerations that they will have. You will need access to electricity for moon bounce/jumpers if you choose to have them and entertainment/music. Food concessions may also need electricity. Many parks have some electrical access, but it is spread out and limited. If you schedule for outside, be sure to check about this. Also check on restroom facilities. You may need to rent a port-a-potty. Check on parking area for outside events. Schools and community buildings typically have adequate parking areas.

9. Have your bookkeeper log in each donation as it is received (we can email you a sample spreadsheet if you'd like). This should be a daily task. At the end of each week, email Eric.Cole@Dandy-Walker.org a copy of your spreadsheet—he will be eager to know how things are going for you. Make copies of all checks and logs including a mailing address for all who donate in cash. The Dandy-Walker Alliance acknowledges all donations in writing so that

individuals may use the written acknowledgement for tax purposes. Checks that come in several weeks prior to the event should be mailed to the Dandy-Walker Alliance for deposit to allowing timely balancing of the individual's checking account. Those that come in near time of the event can wait until the event is over to be sent to the DWA. Expect donations to trickle in for a while after the event. Cash can be taken to a local bank and a certified check can be drawn up.

10. Keep a large three ring binder with all returned participation forms in alphabetical order. This is your back-up and helps us build a database for the Dandy-Walker Alliance newsletter and future events.

11. Thank everyone!

### *Mail out letters, Packets & Sponsorships*

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Mail out packets are given to each participant to mail to friends and family requesting sponsorship. Each packet should contain at least 15 mail out letters and one participant information form. Ideally mail outs should go out six-weeks prior to the event. This will give you the ability to have mail outs arrive at the first of the month pay period and the middle of the month pay period. Most participants will get them in the mail a month prior to the event. Some will be even later than that. It is never too late. You will continue to receive sponsor letters several weeks after the event. Sometimes people will choose to collect money from individuals rather than send out the 15 mail outs. Try to get an address on these donations—encourage them to fill out the bottom portion of a mail out sponsor form for each person who gives contribution with the donor's name and amount contributed for bookkeeping purposes. Also encourage walkers/runners to turn this collected money in **before** the day of the event, if possible. You will still have people who will bring you money and forms that day.

1. When writing your mail out letter be sure to personalize it as much as possible, most people that receive these may have never heard of Dandy-Walker Syndrome and by telling a bit of your story you'll make it more than just the name of a condition to them!
2. Each mail out letter should have a copy of the Dandy-Walker Alliance brochure attached to it. This will explain in more detail what Dandy-Walker is and how it affects people all over the world.
3. Encourage participants to include a handwritten note at the bottom of each mail out when they send them explaining why this is important to them. If they know someone with Dandy-Walker or hydrocephalus they could also include a picture of that person.

4. Contact local printers in your area, explain what you are doing and ask them about donating printing services. Once you have a sponsor mail out letter written -get it, and a copy of the brochure, to your printer. PRINT MAIL OUTS ON A BRIGHTLY COLORED PAPER. Allow a week for printing. Ask the printer to collate the letter and brochure, this makes putting the packets together -much faster.

5. Create and make copies of the participant information form (see sample—or customize your own). This will give you information for your participant data base—1. You will know **who** plans to participate 2. You will have e-mail and mailing information, 3. You will have T-shirt sizes. (Note: CALL 1-877-DANDY-WALKER and speak with Eric or Terri as early as possible to let them know how many T-shirts you estimate you will need by size.) You should ask that these be completed and turned in to you immediately. If you are working with a school, or children in any group, send the participation form home, give them about three days to return it to school, then take the mail out packets to school with each child's name on the packet (separate by grade and homeroom if you can to make it easy for the office). The participation form will give the parents instruction on what to do with the mail outs.

6. Put together 15 sets of the mail out letter/brochure with one participant form and paper clip them together.

7. Thank everyone!

### *Advertising and Getting Participants*

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1. As soon as you set a date and determine a location: Immediately contact civic groups and others that you can talk to about DW. Take mail out packets -with you. Take presentation board and pictures if you have them. Definitely take handout brochures on DW.
2. Contact church organizations that will let you speak to them.
3. Contact scout groups about participating as a unit.
4. Contact local newspapers a month in advance about posting information in “coming events” section.
5. Two weeks prior to event have local papers run an article on Dandy-Walker. You may have the best luck writing the copy and submitting it to them. (Note: CALL 1-877-DANDY-WALKER and speak with Eric or Terri and they can send you a draft from which to work or customize as you see fit.) Include pictures of a local child with DW or hydrocephalus. See our website for links to articles that have been published in other communities for ideas.
6. One week prior to event have newspapers run an article on all of the activities to be held the day of the event. Include pictures of bands, singers, etc. that you may have coming. List other concessions that will be there.
7. Most TV stations will have a community service slot—sign up for this as soon as you have a date—they fill up fast. You would ideally like to have a time slot about three days from your event. Also ask for news coverage the day of the event as soon as you have a date. Send a polite email reminder to the station the week of the event.

8. Ask newspapers to have reporters on hand to cover the event. This too needs to be booked as far in advance as possible. Let them know about dignitaries you will have coming and the presentation of the check at the end of the day.
9. Contact every local, state and federal representative that you can think of about being in attendance that day. BE SURE TO SEND EACH OF THEM A SPONSOR LETTER—THEY ALL TYPICALLY HAVE FUNDS THEY CAN USE TO SUPPORT YOU. Members of Congress love to attend these events and you will want to give them the chance to speak to everyone that day.
10. Contact your local mayor about declaring the day of your event “Dandy-Walker Day”. See sample. This is also good information for the local paper. Be sure to display your proclamation the day of the event. Read the proclamation the day of the event.
11. Make posters or have them printed to distribute two weeks prior to event. See sample pictures. (Note: The Dandy-Walker Alliance has two huge banners we can mail you to use. )
12. Clip and save copies of all advertising. If you plan to make this an annual event, you may want to start a scrapbook.
13. Thank everyone!

### *Details Person*

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1. Assemble sponsorship packets in groups of at least 15.
2. Make at least fifteen signs that indicate the way to the location. Schools have a die cut machine that you can use to make letters. Get these laminated (can be re-used and will also hold up in the event of rain the night before.) You will be responsible for getting these in the ground as early as you think appropriate.
3. Contact Eric or Terri about shipment of banners—we have two . Determine placement location. They should go up two weeks prior to the event.
4. Make a sign to be posted with each banner giving the time, date and location of the event. (see sample)
5. Purchase balloons (gives a festive air) and arrange for a portable helium tank and balloon filler to be delivered to you or the site. We purchased bags of 50 of green, blue and silver from a local party store. You will also need curling ribbon for strings. Designate three people to fill and place these balloons, at predetermined locations at your event, early on the morning of the event.
6. Purchase green and blue plastic table cloths to use on tables (check a dollar store). This is certainly optional, but it helps tie things together with a color scheme.
7. Make signs for each concession and registration.
8. Arrange for the delivery and set up all tables and chairs that you will need. Most churches will lend you tables if your location does not have enough. Be sure you have three tables for registration and DW T-shirt, pins, wrist band sales.

9. Arrange for people to work at each booth, either for the entire event or in shifts. You will need several at the registration booth in addition to your bookkeeper and a helper specifically for them.
10. Pick up keys to location the day before the event if you are using an inside location.
11. Contact local banks or other busy places about wearing a Dandy-Walker T-shirt the day before the event. We found this really paid off as a reminder for people to attend. We even received some additional donations from this.
12. Make four or five donation cans to set in various locations on the day of the event. We used coffee containers (large plastic with lid). We spray painted over the product logo and spray glued pictures of DW children on the outside.
13. Contact a local organization (Rotary, Junior League, fraternal, etc) about handling your food concessions. We had a local women's group partner with a small local restaurant. The restaurant furnished all of the food (he was able to get all of the drinks donated from his Pepsi vendor). His original plan was to donate 50% of sales to DW—which was good since we then had no outlay for any kind of food expense or question about what to do with leftover items. The civic group set up, served and cleaned up. At the end of the day, the merchant donated all proceeds to DW. Whatever you do, keep food concessions as easy as possible.
14. Make arrangements for the rental of jumpers (moon bouncers) if you choose to have these. We made these a "free" attraction. The Chamber of Commerce was asked to make a donation in the amount of the rental charge of the bouncers. Arrange for pick up and return. Also arrange for a few people to set these up. Designate their location for your set-up crew on a floor chart prior to event so they know where you want them.
15. Contact the entertainment. We used a local band and a singing group. For a four to five hour event you will need two groups. Ask that they donate their time. We provided members of each group with T-shirts and lunch. Several of them made donations and others collected sponsors.
16. Establish a schedule for entertainment.
17. Order and pick up awards for laps and money raised (two each – most raised/walked by adult and child or do runners up awards). Talk to local trophy companies about donating these.
18. Prepare and deliver participation certificates (samples available, email Terri if you'd like to use one) to students who participate.
19. Prepare a "laps walk/run chart for day of event. Purchase rubber bands to go on participant's wrist as they complete each lap. Count total number of rubber bands when each participant completes their walking/running. They can come back later and walk more if they want. At the end of the event determine the most laps completed by a child and the most laps completed by an adult. Get this information to the event announcer.
20. Keep an expense spread sheet for all of your miscellaneous purchases for the event so that we can acknowledge these in-kind donations for your tax purposes. This will also give a sense of what it costs to hold a walk/run and you may be able to approach someone in the future to cover these costs.

21. Make arrangements for shipment of the big “presentation check” from the DW Alliance or have one of your own made. Ours was made by a sign maker (who donated all of his work) on heavy foam board) see sample
22. Take lots of pictures the day of the event especially for the award and check presentations and pictures with all the elected officials.
23. Thank everyone!

### *Master of Ceremony/Announcer*

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1. Select a person to act as your Master of Ceremony; a family member of someone with DW or hydrocephalus is ideal. This person will kick off your event with opening greetings and thanks. They will introduce entertainment, dignitaries and elected officials that you choose to single out for this, stories and award presentations. Introduce the reading of the DW day proclamation by the Mayor (better yet – get the Mayor to read it), give some information about children and families with DW/Hydro. State plans for then funds rose. At end of the event present awards for most laps walked—adult and child (or 1<sup>st</sup> place and runner-up) —and most money raised—adult and child (or 1<sup>st</sup> place and runner-up).
2. Present check with the total raised to date at the end of the event.
3. Other duties as assigned.
4. Thank everyone!

### *Bookkeeper*

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1. Log in on spreadsheets information and money received each day. You will keep three spread sheets: one with donors name, e-mail address, mailing address, amount, sponsored participants name ; one with participants name, address; one with T-shirt sizes (estimates of this information will need to be given to Eric and Terri no later than four weeks prior to event so that they can have shirts, wrist bands, and pins made and sent to you. The first two sheets need to be set up to accommodate mail-merge for thank you letters so create a column for donor names, address, city, state and zip code. Keep each respective participant in their own row .
2. Copy checks, send checks received early to the DWA. Keep checks received near the date of the event. Obtain a certified check for cash after the event.
3. Ask your bank to donate the use of zippered bags for the day of the event—one for each concession and one for registration. Get change for each bag.
4. Get someone **who understands your system** to work with you the day of the event. People will bring in sponsor forms and money that day. It will be necessary for you to keep track of who sponsors who and for how much so that at the end of the day you can calculate the person who raised the most money (child and adult). Be sure you bring a calculator or two. You will also need to determine or estimate the grand total at the end of the day. Have paper and markers

and scotch tape available to print the total for the presentation check so we can reuse it. Assign "runners" to collect the money bags for you from concessions, etc. and total amounts in each bag. You can then add these to your sponsorship totals for the grand amount. This will be your most harried day! Get good competent help.

5. Call Eric or Terri, if they are not already there! With your results, they will be eager to share in your success.
6. Thank everyone!

### *Additional Information*

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1. Dandy-Walker Alliance will furnish your event with T-shirts, lapel pins and wrist bands for each participant and extras to sell. Estimates for how many you think you will need are critical since we may need to make these depending on the size of the event.
2. Contact your state representative for the March of Dimes for donation of "goodie" bags and their information to give out to participants the day of the event. We also included business' information from all businesses that made corporate donations in these bags, pens, calendars, anything else you can come up with. We were also able to get mouse pads from the National Organization of Rare Diseases, so think about asking companies for things like that too. We based our asking on 100 participants. Call Eric or Terri for ideas or folks you can contact.
3. Walmart donated a gift card that we used to purchase bottled water for each bag. The balance was used for miscellaneous items (tape, spray glue, some poster board.)
4. We got anything and everything we could donate. Colored copier paper, laminating, poster board, sign making, entertainment, cookies, scripture T-shirts from a church, cookbooks, use of cotton candy machine (also donated supplies to make cotton candy).
5. We had three items donated for a raffle at the end of the day. (Tickets for the drawing ranged from \$.50-\$1.00 depending on item.)
6. Use your imagination!
7. Keep notes about who you ask for what and ideas for next year if you plan to make this an annual event.
8. Try not to prejudge who will give. You will be pleasantly surprised.
9. The average return per mailer sent is \$25.00 Set your monetary goal based on this. How many fliers do you need to send to ensure you reach your goal? **Always remember that awareness is priceless!**
10. We had a young lady (12 years old) who is artistically talented (and also has hydrocephalus) sell packets of note cards that she prepared specifically to raise money for this event. In prior sales (before the event to friends, teachers and family) plus sales the day of the event, she raised \$720. She plans to continue making her cards and perhaps even develop a Christmas line. You can contact her for cards or information on the DW web site. **Taylor Moore, Tay-Bug Cards**

11. Look around in your community for similar skills or other artistic avenues. Paintings or sketches for sale or for a drawing would be great.
12. Be sure to assign someone to take lots of pictures!
13. Thank everyone!

We will make every effort to support your event as much as we can. If at all possible we will have someone from the DW Alliance attend and help on the day of the Walk/Run. If there is anything else we can do or that you need advice or information about please don't hesitate to contact us!

We are able to supply the following to each participant if we have enough notice:

- T-Shirt
- Awareness bracelet
- Lapel pin

Additionally we have the following available to loan for the event:

- 2 Large Banners
- A model of a human brain-This can be used when talking to people about what DW or hydrocephalus are and the parts of the brain it affects.
- Large check to present with the final total amount raised

## Checklist

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### 3 Months prior

1. Put together your event committee. See #1 in planning section for suggestions.
2. Set Date
3. Prepare a list of possible locations.
4. Prepare list of organizations to approach for participants. See #2 in Planning section for suggestions.
5. Prepare a list of organizations to approach about having a booth at the event. Food vendors, local business, etc. Ask them about donating a percentage of their sales for the day.
6. Think about entertainment. Does your location have a facility for a band or other type of entertainment? Consider jumpers to keep children entertained.
7. Prepare a list of elected officials and local dignitaries that you can invite. Politician's and local celebrities often lend their support.
8. Contact local printers and ask them if they'd be willing to donate their services to print and collate mail out packets.
9. Delegate out to your committee some of the lists you've made above and have them start gathering information, sending initiations and making contacts.

### 2 Months Prior

1. Finalize your location.
2. Start speaking with organizations to secure participants.
3. Put together a list of equipment you'll need. Tables, a microphone or bullhorn, calculators, signs (or supplies to make signs), banners, pens, balloons, table cloths, T-shirts and anything else you can think of. Delegate that someone be in charge of getting everything together and to the right place at the right time. Keep in mind any special equipment you might need for entertainment.
4. Write your mail out letter and get it to the printer.
5. Put together participant packets including 15 mail outs and a participant form. Deliver them as needed.
6. Have your bookkeeping person get a spreadsheet set up to start tracking participants and donations. Contact Eric or Terri if you need an example.
7. Secure your vendors and be sure to see what equipment they will need, electricity, tables, etc.
8. Be sure your committee is communicating all information back to you so you can be sure everyone else has the information they need.

## 1 Month Prior

1. Get list of participants to DW Alliance so that T-shirts, wristbands & lapel pins may be sent out.
2. Make signs for the event - Directional signs, Registration signs, Posters, etc.
3. Mail in any checks that have been received.
4. Contact Newspapers and local media to have your event posted on local "Calendar of Events."
5. Contact News Media about covering the Walk/Run and/or doing a story prior.
6. Talk to everyone on your committee, be sure they are on track or find out early if they need help.
7. Talk to local businesses about donating things for participants goodie bags.

## 2 Weeks Prior

1. Follow-up with invited guests to be sure they have your event on their calendar.
2. Put together goodie bags for participants.
3. Follow up with news media-stories should run a week to two weeks prior to the event and then again afterwards.
4. Put together a Event Day Game Plan, task lists for volunteers. A schedule of who is doing what and when and distribute to everyone.

## 1 Week Prior

1. Put up posters.
2. Be sure all equipment is secured and ready to be picked up or delivered.
3. Follow up with everyone, vendors, guests, etc.
4. Put up banners.
5. Mail any checks that have been received to the DW Alliance for deposit.

## Day before

1. Pick up keys to location if inside.
2. Set up tables and as many booths as you can.
3. Get registration tables ready.
4. If you've ordered bouncers get them picked up and inflated.
5. Be sure you have everything required for any entertainment.
6. If vendors want to, let them come in and set up the evening before.

## Samples

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Sample check-donated by local sign company



Sample Sign



Banner Available for loan

Sample Mail out letter-Front



**Dandy Walker Syndrome Fundraiser**

Dear \_\_\_\_\_,

On September 26, I will be participating in a Walk/Run fundraiser in Millport, Alabama, to raise public awareness and promote the need for more research of a birth defect known as Dandy-Walker Syndrome and a commonly associated condition called hydrocephalus.

Dandy-Walker involves an area at the back of the brain called the cerebellum and the fluid-filled spaces around it. The Centers for Disease Control and Prevention estimate that Dandy-Walker occurs in at least 1 in 5000 infants. Although it is one of the most common brain malformations, still little is known about Dandy-Walker and its cause(s); today there is no cure.

Four years ago, Eric and Andrea Cole were blessed with a son, Ryan, born with Dandy-Walker; he soon developed hydrocephalus. After learning that no advocacy organization existed for the Dandy-Walker community, the Cole's united with other families and established the Dandy-Walker Alliance, Inc. as a 501(c)3 non-profit public charity dedicated to providing educational and informational activities, supporting research and organizing events to increase public awareness for Dandy-Walker. Today, the Dandy-Walker Alliance disseminates information in 41 languages to 73 countries around the globe for free. You can learn more about Dandy-Walker and the Alliance by visiting the website at [www.Dandy-Walker.org](http://www.Dandy-Walker.org).

Individuals with Dandy-Walker can have a wide range of manifestations, from quite mild with some children having normal cognition and others never achieving normal intellectual development. Longevity depends on the severity of the syndrome and associated malformations. The presence of multiple congenital defects may shorten life span.

Eric and Andrea do not know what the future will hold for Ryan. He is a happy little boy who attends a special preschool year round where he is learning to talk, use sign language and play like any other child. He says prayers with Mom and Dad every night before bed and tells his family that he loves them in his own special way.

Please sponsor me as I run/walk to fund efforts to increase awareness and promote the need for more research into Dandy-Walker for so many children like Ryan. You may enclose your tax-deductible donation in this self-addressed flyer and return it to the address below. All donations will be acknowledged in writing for you to use as a receipt for your tax records. Checks should be made to the Dandy-Walker Alliance, Inc.

Thank you for your generous support and for helping me advocate for those who can not advocate for themselves.

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Sponsor Name \_\_\_\_\_

Address \_\_\_\_\_

I will sponsor you for a flat amount of \$ \_\_\_\_\_ I will sponsor you for \$ \_\_\_\_\_ per lap

**Please make checks payable to Dandy-Walker Alliance**



**From:**

**Dandy-Walker Alliance, Inc.  
c/o R. Scott Cole, CPA  
P. O. Box 278  
Millport, Alabama**

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**From:**

**To:**