



FAMILY TEAM CAPTAIN GUIDE

Your support of the WALK provides the resources for the Hydrocephalus Association (HA) to fulfill and expand its mission to find a cure for hydrocephalus and improve the lives of those affected by the condition. We will be accomplish this by collaborating with patients, caregivers, researchers and industry, raising awareness, and funding innovative, high-impact research to prevent, treat and ultimately cure hydrocephalus.

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WELCOME

Thank you for participating in the Hydrocephalus Association (HA) WALK to End Hydrocephalus in your community, and serving as the leader and Team Captain of a Family Team. Participating in the HA WALK is a great way to connect the local hydrocephalus community, increase awareness of the condition and our association, and ensure HA has the resources required to deliver high caliber program services in support, education, and advocacy and to fund cutting-edge research.

The WALK to End Hydrocephalus is the Hydrocephalus Association's largest, fastest growing fundraising event. It has grown tremendously in the past few years. In 2010, HA had 20 WALKS raising \$504,000. Now, HA hosts over 40 WALK events that raised more than \$1.7 million last year—half of the association's total annual revenue.

What makes this statistic even more amazing? All HA WALKS are 100% volunteer initiated and volunteer coordinated. HA does not have offices across the country with paid staff coordinating fundraising events—its total staff consists of 17. The unprecedented growth of HA and the WALK program would not have been possible without the tireless dedication and passion of HA's local volunteer WALK Chairs and Co-Chairs. HA volunteer leaders, WALK sponsors, 1,000 Team Captains and 15,000+ participants are bringing us one step closer to a cure!

Thank you for your time and support. The money you raise and the awareness you bring to this cause is critical to increasing HA's capacity to fulfill its mission. Enjoy the WALK to End Hydrocephalus! Accept the challenge and share the victory!

With gratitude,

Randi Corey

National Director of Special Events



The Hydrocephalus Association (HA) was founded in 1983 by parents of children with hydrocephalus who were determined to give their children a better future. For its first 25 years, HA's primary focus was support and education. In 2009, HA added funding research to its mission. Since then HA has committed over \$6 million to research, making it the largest non-profit, non-governmental funder of hydrocephalus research in the U.S.

Thanks in part to the WALK to End Hydrocephalus program, HA's annual revenue has doubled in the past four years, now totaling over \$3.3 million. This growth has greatly increased HA's ability to continue to deliver superior program services and fund cutting-edge research available.

TOP 10 RESPONSIBILITIES

OF A WALK TO END HYDROCEPHALUS TEAM CAPTAIN

- 1 **Recruit team members** to participate in the Hydrocephalus Association WALK to End Hydrocephalus and raise money.
- 2 **Set a fundraising goal** for yourself as a Participant and for your Team. (Suggested minimum fundraising goal for Team Captain: \$250; suggested minimum goal for the Team = # of Team Members x \$150 each.)
- 3 **Update your Team WALK to End Hydrocephalus web page** and your Personal WALK to End Hydrocephalus web page. Ensure team members update their Personal WALK to End Hydrocephalus web page, too.
- 4 **Set up a schedule of emails and communications with Team members** to keep them informed of the Team's progress toward its goal and to keep the WALK to End Hydrocephalus and fundraising at the top of their "To Do" list.
- 5 **Inspire and motivate** your Team members by sharing your connection to hydrocephalus, the Hydrocephalus Association and your passion for this cause.
- 6 **Make it fun** by providing incentives and special recognition for Team members who reach their fundraising goal.
- 7 **Promote and publicize the WALK to End Hydrocephalus** and your Team's participation by using social media (Facebook, Twitter, Instagram, Google+, LinkedIn) and email.
- 8 **Share Important WALK to End Hydrocephalus Information with your Team members**, including information sent to you by your local HA WALK to End Hydrocephalus Chair (and the important "nuts and bolts" information sent to each registered Team Captain one week before the WALK to End Hydrocephalus.)
- 9 **Host a team fundraising event** to support your Team goal and raise awareness for the HA WALK. (See Fun Fundraising Ideas from A to Z on the WALK to End Hydrocephalus Resources web page.)
- 10 **Thank all of your Team members and donors** with a personal call, email, shout out on social media—or best of all, a handwritten thank you note.

TEAM CAPTAIN RESPONSIBILITIES

GETTING STARTED

THANK YOU for stepping up to be a Team Captain at your local WALK to End Hydrocephalus. Teams help people rally around someone they know living with the challenges of hydrocephalus. With friends, family, extended family, co-workers, and neighbors at your side, you make a much bigger impact than you could alone.

Serving as a Family Team Captain primarily consists of four steps: plan, recruit members, raise money and give recognition. This guide will provide you with all of the information, resources and ideas you'll need to lead a successful WALK team.

DEVELOP YOUR PLAN

Set your Team's goals for the number of team members you are going to recruit and the amount you are going to fundraising. Challenge yourself! If you are a new Team, decide how many team members you want to recruit and multiply that by at least \$150.

Example: If you plan to have 10 team members your team's goal should be at least \$1,500. (The average WALK participant across the U.S. raises \$127.) If you are a returning Team from a prior year, make your goal higher than your last total. Set a stretch goal!

REGISTER YOUR TEAM

Register your Team (and yourself) online at www.hydroassoc.org/walk

When you register online you'll set up your WALK Team and personal Participant web page at the same time. When registering you'll need to enter the goal for the number of Team members and the Team's fundraising goal. Again, best practices suggest your Team fundraising goal should be # of team members x \$150 each.

Give some thought to your Team's name before registering—many team names are as simple as the Ryan Family Team. Some are more descriptive—Harry's Hydrocephalus Warriors or Sam's Shunt Busters.

CUSTOMIZE YOUR TEAM AND PERSONAL PAGES

The Team WALK web page is automatically produced as part of the registration process when you select "Start a Team" during registration. Your personal Participant WALK web page is automatically created at the same time. ([Step-by-step instructions to register yourself and your team can be found in this guide](#))

You can easily customize both pages by clicking the "Participant Center" tab. Follow the step-by-step instructions to change the title, upload a personal picture and share your story about why you're leading a HA WALK Team and why HA's mission is important to you. You may use the standard text that appears on the Team WALK web page, you may add text about your connection to hydrocephalus or you may replace the standard text entirely with your own, personal story.

TOP TIP

HA suggests you review the Step-by-Step Instructions to Register or the Quick Start Registration Steps before starting the Registration process for you and your Team.

TEAM RECRUITMENT

RECRUITING YOUR TEAM MEMBERS

Team members will consist of friends and family who participate in the WALK to End Hydrocephalus on event day, walking with you and raising money to support your team's total. Fundraising is easier together, and the more team members you can add, the higher your team's fundraising results.

START A LIST OF PROSPECTIVE TEAM MEMBERS

HA WALK teams may be comprised of one person or 1,000. There is no minimum number of people required for a HA WALK Team—but the most successful teams have 10 or more team members raising money. Team members may be family, extended family, friends, neighbors, co-workers, Facebook friends—anyone and everyone!

NEED IDEAS FOR PROSPECTIVE TEAM MEMBERS?

Review your email address book, your holiday card list, your business card file, your personal address book (the one you keep in your junk drawer in the kitchen), your church directory, your club directory, your Rolodex, your Facebook friends, and your followers on LinkedIn, Twitter, Instagram, and other online platforms. Don't forget your neighbors! All of these people are great prospective Team members.

ASK PEOPLE TO JOIN YOUR TEAM IN PERSON

Remember the old axiom: "They can't say yes unless you ask." Please don't say "no" for them by not asking. Don't worry about asking busy people—everyone is busy – and busy people get things done! Once they've committed, strongly encourage them to register, which will generate their own personal WALK Participant web page where they can utilize HA's online fundraising tools.

TOP TIP

The most successful family teams add a personal photo and replace the standard text to tell their story on their Team web page.

HELP TEAM MEMBERS REGISTER ONLINE AND JOIN YOUR TEAM AT HYDROASSOC.ORG

To start raising money online, you and your team members must be registered. Once you're registered and in your "Participant Center," you can send a recruitment email to your contacts. This email will give them a link to your personal and team pages, where they can register.

If you experience any problems, please contact the HA national office by email walk@hydroassoc.org

TOP TIP

List at least twice as many prospects for your Team as your goal for the number of Team members.



STRATEGIES FOR SUCCESS

As a Team Captain, you can feel good knowing the money you and your team raise is helping provide support, education, advocacy, and cutting-edge research for the 1 million+ people living with hydrocephalus in the U.S. Research is showing results now. HA-funded research has developed a protocol for hospitals which has reduced shunt infection rates by 34%! Always remember you, and your team members are an integral part of the fight against hydrocephalus.

MOTIVATING YOUR TEAM MEMBERS

While the WALK to End Hydrocephalus is a time to celebrate your team's success, it's the weeks leading up to the WALK when Team members are registering and raising money. Everyone on your team will hopefully fundraise above and beyond their own initial donation. As a Team Captain, it's your job to encourage all members of your team to help you meet your Team fundraising goals.

LEAD BY EXAMPLE AND SET YOUR OWN PERSONAL FUNDRAISING GOAL OF \$500 OR \$1,000

Your team will follow your lead. Set your personal fundraising goal high. Ask team members to set a personal fundraising goal of at least \$150 to \$200. Remind them that raising \$200 is asking 9 people for a \$20 donation and adding their own donation of \$20. If your team goal is \$2,000, having 10 team members each raising \$200 is a quick way to get there.

SHARE YOUR STORY WITH EVERYONE ON THE TEAM

Keeping your connection to the mission front and center of your fundraising and team building efforts will help keep the team motivated.

GIVE YOUR TEAM MEMBERS A HEAD START ON RAISING MONEY

Use the documents on the WALK Resources web page (Fundraising A-Z, Letter Writing

Campaign, 20 facts about hydrocephalus, or Fundraising Tip Sheet) and share them with your team members.

REMIND TEAM MEMBERS OF HA'S INCENTIVE PRIZE PROGRAM

All team members who raise a minimum of \$75 will receive an official WALK to End Hydrocephalus T-shirt when they check-in at the event. In addition, HA offers incentive prizes for different levels of fundraising. Each person that registers for your team will automatically receive emails about our incentive prizes. You can also view this year's incentive prizes in the "Resources" section of your local WALK web page.

ASKING TIPS

When to ask? If asking in person, the best times are on Fridays or on the 1st or the 15th of the month—paydays for many! If asking via email, send your email to arrive early in the week.

How much should you ask for? HA suggests starting with a "higher" ask—\$75 or more. They can always give less. No one was ever insulted because you asked them for a large donation! If anything they're flattered that you think they can do that.

TEAM FUNDRAISING (cont.)

RECOGNIZE YOUR TEAM MEMBERS

Recognizing your team members leading up to your WALK to End Hydrocephalus will help keep them motivated in their fundraising and make them feel appreciated and successful.

- Send weekly emails and updates to your team members about your progress toward meeting the team goal. This is a great place to announce any WALK details as well.
- Share your successes each time a team member and/or your team hits a milestone in your fundraising efforts. Halfway to your goal? Great—let others know through your regular email updates, on your Team’s WALK web page, and on Facebook, Twitter and other online platforms. Highlighting your team’s top fundraisers for their success and creative fundraising ideas encourages others and may also foster some friendly competition.
- Use the WALK Facebook page and Twitter handles to give a shout out to team members beyond your personal social media accounts. Ask your WALK Chair if your WALK has a Twitter account, since not all of our WALKS are using Twitter.
- Consider small incentive prizes for Team member accomplishments—they don’t need to be expensive. For example: for every \$20 raised by each Team member during the week of (date to date) you’ll

receive a chance in a drawing for a _____ . (Be specific about the start and end deadlines!)

CREATE A TEAM T-SHIRT

Many HA WALKS conduct a Team T-shirt Design Contest at the event. Contact your local WALK Chair to ask if your site holds a Team T-shirt competition. Many team t-shirts are very clever, many are very touching. Offer the t-shirt free to all of your team members who register and raise money. T-shirts can be obtained very inexpensively at places like Vista Print (no minimum number required.) Having a team t-shirt makes recruiting team members easier AND gives your team a visible presence at the WALK.



TOP TIP

Do not require your team members to raise a specific amount to obtain your Team t-shirt. If you attach an amount to the shirt, most team members will just write a check for the amount and not raise any additional money.

POST-WALK THANKS AND RECOGNITION

After the WALK, don't forget to send everyone a final update thanking them for a job well done and announcing which team members exceeded their fundraising goals. Hand-written thank you notes to tell people how much you appreciate their efforts go a long way. When thanking team members and donors always remember to emphasize how their contributions make a difference.

Consider sending this handwritten on a note card, although an email thank you is acceptable.



Dear first name:

Thank you so much for joining our Hydrocephalus Association (HA) WALK to End Hydrocephalus Team, [insert name of Team]! You were an integral member of our Team, which was extremely successful, with more than X team members, raising over \$XXXX. This amazing result was only possible because of you and your efforts on behalf of HA and its mission. As the parent of a child with hydrocephalus (or as someone living with hydrocephalus) your willingness to support this cause touches me deeply and I cannot thank you enough.

I hope you'll consider joining us again next year as we strive to exceed this year's incredible results! It wouldn't be the same without you!

Warmest regards,

Your Signature

TEAM EMAIL/LETTER SAMPLES

If you're unable to recruit all of your WALK Team members face-to-face you can always use email as a "Plan B." Below are two email templates to get you started. Or, as always, feel free to write your own.

FROM:
TO:
Subject Line: It's that time of year...!

Re-Recruiting Previous Team Members

Dear [\[insert name\]](#),

Believe it or not, it's that time of year again! The [\[insert site name\]](#) HA WALK to End Hydrocephalus is coming up and I'm reaching out to ask you to join our team, [\[insert team name\]](#), again this year. Our team was amazingly successful last year with [XX](#) WALK participants, raising a team total of [\\$XX,XXX!](#) (The overall WALK raised more than [\\$XX,XXX.](#)) You were an integral part our team last year and I'm hoping that you'll be joining us as we go for a record breaking total this year—[\\$\[insert team fundraising goal.\]](#)

To join our team go to [\[insert the URL link to your team's HA WALK web page\]](#). Click "Join Team" and follow the prompts.

Know anyone who may be interested in participating on our team? Please ask them! The more the merrier. (Please make sure they register online, too.)

Include the following if it applies to your WALK team—[\[We're going to have a Team T-shirt for our team members, but we need all of our team members to register so we can plan accordingly.\]](#) Raise \$75 or more and you'll receive HA's official WALK T-shirt, too. It can be as easy as asking 4 friends or family members to each sponsor you for \$20.

If you're unable to join us in person this year, join the team as a Virtual Participant. Virtual participants register as team members—and the money you raise will be added to our Team's total.

Thank you for your support—and thank you for helping make this year's [\[name of team\]](#) team the best ever!

[\[Insert Team Captain's Name\]](#)

Team Captain—[\[Insert Name of Team\]](#)

FROM:
TO:
Subject Line: [I/We] Need You

Dear [insert name,]

I am emailing you to ask you to support me and a cause that is very near and dear to my heart. I am forming a team to participate in the Hydrocephalus Association (HA) [WALK city name] WALK to End Hydrocephalus on [insert date] in [location.]

Why is the Hydrocephalus Association such an important cause?

You may (or may not) know, that [insert your own connection to HA and its mission] (Example: “You may, or may not, know that I was diagnosed with hydrocephalus when I was a child and I have lived with this condition for many years.” Or “...my son/daughter/mother etc. has been living with a condition called hydrocephalus since birth—or since she was three years old.)

Hydrocephalus is an abnormal accumulation of cerebrospinal fluid within the brain. When cerebral spinal fluid is overproduced it builds up and puts intense pressure on the brain. The most common method of treatment is implanting a medical device, called a shunt, to drain the excess fluid. Although a shunt helps control the fluid buildup a shunt is not a cure. Having a shunt may result in multiple surgeries throughout a patient’s life—dozens are common and 100+ is not unheard of.

Optional: add a sentence or two re: your or your loved one’s experience with hydrocephalus. (Example: “I’ve been very fortunate and have only had to undergo XX number of surgeries.” Or “My son has endured XX surgeries in the past X years.”)

That’s why I’m forming a WALK Team for the 20XX HA WALK here in [name of area.] I hope you [and your spouse, etc.] will join [my/our] team [insert name of team.] What do team members do? Team members:

- Register to participate
- Raise money to fight hydrocephalus (our goal is for each Team member to raise at least \$150) and
- Have a great time with family and friends—accept the challenge and share the victory!

To join our team go to [insert the URL link to your team’s HA WALK web page]. Click “Join Team” and follow the prompts.

Once you’ve registered we’ll share great ideas and tips on fundraising to maximize your potential. Let’s make [insert name of team] one of the biggest and best! (Optional: We’re planning on a Team T-shirt for all team members but we need everyone to register so we can plan accordingly.) WALK participants raising \$75 or more will receive the official HA WALK T-shirt, too!

If you have any questions please contact me at [insert email address] or [insert phone number.] [I/We] look forward to your joining us on Team [insert name of team]!

[Insert Name of Team Captain]
Team Captain—[Name of Team]

TEAM EMAIL/LETTER SAMPLES (cont.)

FROM:
TO:
Subject Line: [I/We] Need You....!

Inviting Friends to Donate

Dear [insert name]:

I am participating in the [insert site name] Hydrocephalus Association (HA) WALK to End Hydrocephalus on [insert date of event.] As you may know, [insert brief information on why this cause is important to you]. (Example: As you may know, my 7-year old son Donny, was diagnosed with hydrocephalus at birth. To date, Donny has endured 5 brain surgeries trying to keep this condition under control.) Hydrocephalus is an imbalance in the absorption of cerebral spinal fluid which circulates around the brain and spinal cord. When hydrocephalus causes the fluid to build up, it places the brain under intense pressure. The only treatment for this condition involves brain surgery—most often to implant a medical device called a shunt in the brain to drain the excess fluid. But a shunt is not a cure.

The Hydrocephalus Association is the U.S.'s largest non-profit organization dedicated to hydrocephalus. Its mission: to find a cure for hydrocephalus and improve the lives of those affected by the condition. In addition to continuing to provide superior support and education service, HA is also the largest non-profit, non-governmental funder of hydrocephalus research in the country.

The WALK to End Hydrocephalus, which raised almost half of HA's total annual revenue last year, is integral in ensuring HA has the resources required to fulfill its mission. But that's only possible with the support of people like YOU!

Please donate to sponsor my participation in the HA WALK. My goal is to raise at least \$150 [or insert your own fundraising goal.] Your donation of \$25, \$35, \$50 (or whatever you can give) is very much appreciated. On behalf of my [insert connection to the mission] (Example: On behalf of my son, Donny, thank you for your support. Or, on behalf of myself and the one million Americans living with hydrocephalus, thank you!) Please use the link to my HA WALK Web Page [insert link to your WALK web page here] to make a donation using a credit card. Or you can pop a check in the mail to: [insert mailing address.]

Thank you for caring and for your support.

[Insert participant's name]

Update Team Members on Your Fundraising Status

FROM:
TO:
Subject Line: We're almost there!

Dear Teammates,

With your support, [Insert Team Name] has raised \$[insert amount] for the Hydrocephalus Association WALK to End Hydrocephalus.

We still need your help to reach our team fundraising goal of \$[insert team goal amount]. Please continue to send out donation emails, post a link to your personal fundraising page on Facebook, tweet about our upcoming WALK to End Hydrocephalus using #HAWALK, and encourage others to join our team and WALK with us on [insert date].

Keep up the good work!

[Name of Team Captain]

Team Members who have raised \$0

FROM:
TO:
Subject Line: It's not too late...

Thank you for joining [insert name of team] team for the Hydrocephalus Association (HA) WALK to End Hydrocephalus this [insert month]. We are excited for the big day. It's not too late to reach your personal fundraising goal of \$__. I am following up with all of our team members who are not showing any contributions beyond their own initial donation. If you have collected funds, thank you so much for your efforts so far. Please bring any money collected to the HA WALK to turn in at the Participant Registration/Check-In. (Or, contact your local volunteer WALK Chair to make arrangements to turn it in before the event.)

Below are some tips to raise money to increase our Team's total and—more importantly—to fund the mission of the Hydrocephalus Association: to cure hydrocephalus and improve the lives of those affected by the condition. More than one million Americans are counting on you!

- Log in to your WALK Participant's web page and use the online fundraising tools, including email templates, to send an email to family/friends around the country—send to 10 people right now. Ask each of them to support you on WALK day with \$X amount.
- Post a message on Facebook promoting your participation and asking for donations (connect your “ask” back to your connection to hydrocephalus—ask for \$1 or \$5 for each surgery you or your loved one with hydrocephalus has endured, or ask for \$1 for every day your loved one with hydrocephalus has spent in the hospital. Don't forget to include the link to your personal WALK page!
- Host a fundraising event in the office (with permission, of course!): a bake sale, pizza sale, ice cream social, or dress down day. I am more than happy to email you additional fun ideas as well as advice on how to do them.

Thank you for your support!

[Name of Team Captain]

TEAM MEMBER FUNDRAISING TOOLS

THANK YOU for joining a WALK team and supporting Someone living with hydrocephalus.

When you participate in the Hydrocephalus Association WALK to End Hydrocephalus, you raise money to provide support and education for people in your community. Please know that the money raised with the HA WALKS is being used wisely and well. Although the average WALK participant raises \$127 many participants raise \$200 or more. Top fundraisers raise \$1,000+. What's their secret? Unfortunately, there is no "magic pill" for fundraising. The most successful

fundraisers use a combination of the tips we share in this guide, which are the result of years of fundraising experience by HA WALK participants. They've learned by trial and error what works and what doesn't.

If you have a terrific fundraising idea that shows extraordinary results, we would love to hear it! Please share it with HA staff at walk@hydroassoc.org.

- 1 Identify Potential Supporters:** The first step is to develop a list of potential donors. For each donor, decide how you will solicit their support for your participation in the HA WALK and how much you'll ask for.
- 2 Ask using a letter writing campaign:** Experienced participants and teams have learned that one of the most effective ways raise money is using a letter writing campaign. Send a letter to everyone you know sharing your and/or your family's personal connection with hydrocephalus and ask for their support. While you may find it difficult at first to share your personal story and ask for donations, you may be surprised by the responses you receive from people. Many families report that when people send donation checks they include a note thanking the participant for asking. Some of these notes mention that when you or your loved one was first diagnosed with hydrocephalus, they wanted to do something to help but didn't know how. Your request for a donation has given them a way to help! Letters may be sent via U.S.

postal service, email—or both! You also have the options of using the online fundraising tools on your personal WALK web page to upload email addresses from your online

TOP TIP

Letters sent via U.S. postal service should be mailed on Friday or Saturday for arrival early the next week. People are more likely to open mail and pay attention to it earlier in the week.

address books and send emails directly from the system. Steps for conducting a Letter/ Email Writing Campaign are provided in this guide.

NOTE: On average it takes three asks to obtain one donation.

- 3 Ask Face-to-Face:** Asking for donations and sponsors face-to-face is very effective. It's

much easier to ignore an email or send a quick “sorry I can’t help” than it is to say “no” in-person. There are several types of in-person “asks” you can make: a direct donation, sponsorship of your team, hosting a fundraising activity or helping advertise the WALK. If your child has hydrocephalus (and they’re willing), bring them with you for in-person asks. Many experienced WALK participants have had success asking medical professionals and local business leaders for a donation. These can include your doctor, your child’s doctor, area restaurants, your dry cleaner, hairdresser, auto mechanic, veterinarian, dentist, etc.

4 Keep Good Records: Make a note of people who promise to donate so you can follow up should it slip their mind. A “hard copy” of a walker donor form, available on your local WALK site’s web page, is useful for this purpose.

5 Advertise the WALK: Need WALK posters to put up in your office, school or elsewhere? Contact your local volunteer WALK Chair—s/he will be happy to give you posters, flyers, or WALK brochures to distribute.

Find your local volunteer WALK Chair by contacting the Hydrocephalus Association’s national office at [888-598-3789](tel:888-598-3789), or visit to your local WALK’s web page.

6 Creative Asks for Specific Amounts: Here are some examples of how a participant (you and your team members!) can raise \$300 (or more):

\$50 Ask two family members (spouse, parent, grandparent) for \$25 to contribute to your WALK to End Hydrocephalus participation

\$25 Ask a local business you patronize often (dry cleaner, hairdresser, barber, accountant, veterinarian, etc.) to donate to your WALK participation.

\$75 Ask 3 co-workers to donate to your participation in the WALK.

\$50 Ask your boss for \$50 to support your participation in the WALK.

\$50 Ask your next door neighbor (both of them!) to make a donation to you.

\$25 Ask your best friend to donate you (Even if s/he is walking on your team!).

\$25 Ask your sibling(s) to donate.



TEAM MEMBER FUNDRAISING TOOLS (cont.)

7 Social Media: Social media is one of the most powerful and effective ways to raise awareness for hydrocephalus and to get the word out about your WALK and your WALK team.

 Each WALK has a Facebook page. Make sure you have Liked the page. Then check it regularly for updates and posts you can share through your personal networks.

 Many WALKS have Twitter accounts and some have Instagram accounts.
 If your WALK uses these platforms, make sure you are following them.

For Social Media posting ideas, check out and download our sample images on the resources tab of the WALK page.

Use your personal accounts to reach out to all of your friends and followers. Make sure you tag your WALK page or Twitter profile to extend your reach.

Create a Facebook Event and invite your entire Facebook network to join or support your team. Don't forget to include the link to your personal or Team page and ask people to support you on WALK day.



Most importantly, post and tweet regularly. Let people know why you are raising money for your team.

- Share posts from the main HA Facebook page or your WALK page and always include the link back to your personal WALK page to drive donations.
- Share videos from HA's YouTube channel.
- Share HA's educational resources from our website that you like or have helped you.

The more you post, the more your friends and family may be compelled to support you on WALK day!

TOP TIP

Thank donors by tagging them publicly on social media. It gives them appropriate recognition for their support and it serves as a great reminder to those who haven't donated yet.

Sample Posts and Tweets

 Username
March 22, 2017 ✨

We need a cure to end this life threatening, life changing condition. Please make a donation on my personal HA WALK to End Hydrocephalus web page [\[insert personal page URL\]](#). #HAWALK

Like · Comment · Share

 Username
March 22, 2017 ✨

Hydrocephalus is the leading cause of brain surgery in children. Please support my participation in the HA WALK to End Hydrocephalus web page [\[insert personal page URL\]](#). #HAWALK

Like · Comment · Share

 Name ✓ 

Help me reach my goal of \$ _____ for my HA WALK to End Hydrocephala team. Click [\[insert personal page URL\]](#) to make a donation. #HAWALK

 Name ✓ 

Living with hydrocephalus often means multiple brain surgeries—dozens are common, 100+ is not rare. Help HA find a cure—donate today at [\[insert personal page URL\]](#) #HAWALK

DOUBLE THE DOLLARS WITH MATCHING GIFTS

Many companies match employee donations. Ask all of your donors if they work for a company that offers a matching gift program. If any of your donors work for a Fortune 500 or Fortune 1000 company, their employer very well may offer a matching gift program. If a team member works for a matching gift company, encourage him/her to ask for donations from colleagues which will be matched—doubling the dollars. Some matching gift programs have specific criteria which must be met—minimum donation amount, annual cap on charitable donations, etc. Please ask the donor who works for the matching gift company to contact their HR department to obtain the process for initiating a matching gift request.

PLEASE NOTE: The Hydrocephalus Association cannot initiate a matching gift. It must begin with the employee/donor.

See a list of matching gift companies on page 28.

RAISING MONEY WITH A LETTER WRITING CAMPAIGN

Most of the HA Family Teams raising \$1,000 or more use a letter writing campaign as their primary fundraising technique. The primary functions of a letter writing campaign are to: 1) ask the reader for their financial support—a donation for your WALK; and 2) increase awareness and educate the public about

hydrocephalus. One of HA's biggest obstacles is the public's lack of awareness about the condition. Most people have never heard of hydrocephalus, nor understand its seriousness. By the time the reader has finished your letter, s/he should know a lot more about hydrocephalus.

Follow these simple steps to create your own letter writing campaign and reach your fundraising goal. **MAKE SURE YOU REGISTER FIRST!**

- 1 Write the letter:** Your own letter comes from your heart. As one parent writes, "Someone's going to ask you to donate to something. It might as well be me. I can think of NO BETTER CAUSE! Please, make the Hydrocephalus Association your cause to support." Tell your family's story—how hydrocephalus has impacted not only the patient, but every member of the family. (See pages 3 to 7 for sample letters.)
- 2 Make copies of your letter** (If using Postal Service for delivery):
 - Photocopies of your letter are totally acceptable.
 - Sign each letter individually; perhaps with a personal closing, "Thanking you in advance for your support". Make sure to leave the signature block blank (do not use an electronic signature).
 - Print copies of the HA Fact Sheet included in this document to send with the letter.
 - Enclose a self-addressed envelope for their reply (stamped, if possible).

- 3 Mail and/or e-mail the letter to:**
 - Family and extended family
 - Friends and neighbors
 - Co-workers and acquaintances
 - Business associates and vendors (go through your Rolodex and business card file)
 - Clubs, organizations and classes to which you or your family members belong

If you need help preparing your mailing, organize a letter addressing party. Pull the entire family together to sign, stuff, stamp and address your envelopes—even the kids can help! You'll be surprised what people will do for free food.

Mail or email your letters, ideally eight weeks before the WALK to End Hydrocephalus. But if you're running late, don't despair. You have up to 4 weeks after the event to finish collecting donations.

SHARING IS CARING

LET'S DO THIS!

- 4 COLLECT YOUR DONATIONS:** Nothing is quite as exciting as receiving your mail or checking your WALK to End Hydrocephalus webpage and seeing donations begin to arrive! You can expect to raise approximately \$600–\$800 with a letter writing campaign. Some families have raised \$20,000 or more!

You are able to enter offline donations in your participant center so that they appear on your personal and team page. Call your local WALK Chair if you need assistance doing this.

- 5 Attend the WALK to End Hydrocephalus!** Have fun! Join your teammates and others who are walking to make a difference!
- 6 Thank you notes:** Let each one of your donors know how much you appreciate their support. Use this occasion to

announce how much your family team raised and the total pledges for the WALK to End Hydrocephalus.

Questions? Need more help? Contact the Hydrocephalus Association at:

4340 East West Highway
Suite 905
Bethesda, MD · 20814
Toll Free: (888) 598-3789
Telephone: (301) 202-3811
www.hydroassoc.org
walk@hydroassoc.org



FUNDRAISING IDEAS FROM A-Z

Use the ideas below to increase your personal or team total for the WALK to End Hydrocephalus!

Start Now: The earlier you begin fundraising, the better off you'll be. You'll be able to exceed your personal or team goal in a big way! Remember: they can't say "yes" until you ask!

LETTER WRITING CAMPAIGNS—ASKING FOR CASH CONTRIBUTIONS

Make Your Own Contribution: Lead the way by making your donation first.

Ask for the right amount: Really think about your "ask" before making it.

Ask electronically: Utilize the great tools on your WALK to End Hydrocephalus webpage.

Neighbors: Write to all your neighbors on your block or in your building. Ask them to make a donation.

Use color paper: Ask using a Letter Writing Campaign using color paper. Send them in colored envelopes too. Make sure to use your personal return address in your letters so they'll be opened!

Tell your family's personal story: How hydrocephalus has affected the lives of everyone in your family—and ask for support! Be very real about the challenges of living with hydrocephalus.

Clubs and Organizations: Send a solicitation letter to your local Knights of Columbus, Lions Club, Rotary Club, Kiwanis, etc. They support individuals in their communities.

PERSONAL SERVICES

Babysitting: Ask them to donate what they would have paid a sitter.

Errand boy/girl: Offer to be your friends' and/or coworkers' personal assistant for a day in exchange for a large donation. \$250 or more!

House Sit: Need a warm body to stay at your place while you are away. Ask them to donate what they think is appropriate

Neighborhood Chef: Are you a gifted amateur chef? Prepare a gourmet dinner for 4 in exchange for a donation.

Cooking lessons: Give 5 friends a cooking lesson at \$35 each—enjoy the outcome together with wine!

Neighborhood Chores: Are you a Mr. or Ms. Fix-It? A lot of your neighbors would probably rather pay you than someone else.

ARE YOU A PET LOVER?

Organize a pet birthday party: People love their pets and they even love their friends' pets. Ask guests to bring donations instead of toys or treats.

Pet Sit: Are your neighbors going away? Offer up your services and ask them to donate what they would have paid at the kennel to your WALK to End Hydrocephalus total.

Walk your neighbor's dog!

GIFT GIVING IDEAS

Birthday/Anniversary/Wedding/Holiday Gift

Donation: It will be a lot easier for your friends and family to write you a birthday check to Hydrocephalus Association instead of spending hours trying to shop for you.

HOUSE PARTY FUN!

Host a Movie, TV Show Premier or Finale Party at your House.

Game Night: Call your card-playing friends and invite them over for poker night! Or a bunco night. Get out those board games and start playing

Theme Party/Dinner: Hold a theme party for 10 or more of your friends. Have each guest donate \$50.

Voice Mail Message: This will alert everyone who calls you at home that you're up to something special

Wine and Cheese Party: Host a party at your home, collect donations after everyone has sampled the wine!

Delegate: Give 10 of your friends a donation form and ask them to help raise money for you.

YOU PREFER SELLING?

Inspirational Bookmarks: Create them and sell them to your friends and family.

Lemonade Stand: Ask your kids to set up a lemonade stand.

Bake Sale: An oldie but goodie! host a bake sale with you and your friends. Ask if you can hold it at work. Or you can even hold it in

conjunction with your garage sale.

Garage Sale: Gather that extra stuff up and ask your friends to do the same. All the money raised can go toward your fundraising goal!

Used-Book Sale: Everyone has books that have been sitting on shelves, in the attic or in basement collecting dust

Raffle: Everyone that contributes is entered into a raffle to win a special item such as a homemade quilt or baseball tickets

Creative Friends: Find a local artist or ask a creative friend if they would donate a piece of art or jewelry that you could auction off



AROUND THE NEIGHBORHOOD!

Karaoke Night: Who cares if you can't carry a tune? Spend a Friday night at a Karaoke Bar and sing for donations!

Gym: Ask your gym to place a pledge jar at the front desk!

Happy Hour Party: Ask your local bartender to donate a portion of one day's tips.

FUNDRAISING IDEAS FROM A-Z (cont.)

Cover Charge: Get your favorite local pub, club or other organization to donate all or a portion of their cover charge.

Dance: Secure a donated space, a band to play, publicize it, sell tickets, it's easy and fun and raises lots of money for your team and/or site.

Slim into Shape: Hold a two-month contest at work for everyone who wants to lose weight. Each person pays a pre-determined amount for every pound lost or gained.

Bowling Nights: Plan a fun night of bowling at your local lanes. Ask the owner to waive the cost of bowling so you can collect the "fee" for HA programs and research.

Bunco Night at your company or corporation, or with friends

Church Bulletin: Place an advertisement in your church bulletin/newsletter letting the congregation know what you're up to.

LOCAL BUSINESSES

Who do you do business with? It is time for them to give a little back!

Mechanics: You've given them lots of money to work on your car.

Hair Salon: Ask your barber or hairdresser to donate \$2 of every haircut they complete over the weekend.

Doctor/Dentist/Therapist/Veterinarian/Insurance Agent: Ask him/her to write a check for you instead of the other way around!

Yoga Instructor: You've bent over backwards for them, now it's their turn to do the same for you!

AT THE OFFICE

Office Fundraising Challenge: Speak with everyone in your office and ask them to join a corporate WALK to End Hydrocephalus team.

Corporate Matching Gift: If your company doesn't already have a matching gift ask your company to match the amount of donations you receive from your fellow coworkers.

Company Grants: Find out if your company offers grants to employees who volunteer their time for charitable causes.

Pizza Party: Ask your local pizzeria to donate pizzas and charge your coworkers \$2 a slice.

Putting Green Contest: Construct a putting green in your lobby and charge a fee for employees and/or customers to putt for donated prizes.

Your Donors' Matching Gift: Check with everyone that donates — ask them if they work for a company that matches employee donations.

Dress Down Day: Ask your company to allow an official HA WALK Dress Down Day. For the privilege of dressing down, employees donate \$5 or \$10 toward your WALK total. Your company already dresses down? Try a "Hats On for



Hydrocephalus” or something similar.

Meet the Press: Does your company distribute a newsletter or have interoffice e-mail? Take advantage of these and get the word out about hydrocephalus and the WALK to End Hydrocephalus!!

SOCIAL NETWORKING

Newspaper: Contact your local paper and get an article or a feature story!

Social Networking Sites/Internet Chat Rooms: Post a message on an Internet chat room, or on Facebook.

Computer Screen Savers: Create a WALK Screen Saver and send it to everyone in your company.

Business Cards: Print up some inexpensive business cards on your computer. Have all the pertinent information on the card including your name, the name of your HA WALK, your address and the URL for your WALK web page. Hand these out to everyone you meet!

COLLECT CHANGE

Extra Change Box: Keep a jar near your door and everyday put all your extra coins in it.

Curse Jar: Place a curse jar in your office and whenever someone says a bad word, they have to put a dollar in the jar.

“Extra Change in My Pocket” Box: Create these little boxes for your friends and family and have them place it on their dresser or desk.

Good Karma Tipping Jar: Ask local businesses to put a pledge jar near the register or on their front counter. Tape a picture of yourself to

the jar (or your child if you have a child with hydrocephalus) and a short explanation of why you’re raising money.

PERSISTANCE WILL PAY OFF

Ask as many times as you can: Then ask again! People are busy and can easily miss your email. Don’t be afraid to send emails weekly or bi-weekly to ensure that everyone has an opportunity to see it and respond to it.

Remind Them: If you didn’t receive an answer the first time you asked, ask again! Your potential donors may need a little coaxing. Many times they intended to donate—it just got away from them!

Beneficiaries: Educate yourself on how the money raised is spent. Have some facts and statistics about hydrocephalus at your fingertips. (The money raised with the WALKs funds support and education as well as vital research aimed at finding the answers to this complex, complicated condition.) You’ll be asked where the money is going and it will be very impressive to a potential

donor if you’re able to speak eloquently about it.

(Contact the HA National office or check HA’s webpage—www.hydroassoc.org—for statistics and information.)



SETTING UP YOUR TEAM AND PARTICIPANT WEB PAGES

QUICK START REGISTRATION STEPS

Go to www.hydroassoc.org/walk

On the “WALK Schedule” choose your local WALK site from the list.

Click the “Register” button.

The WALK site’s web page will open.

Then click the registration type that applies to you and follow the prompts.

(NOTE: If you’re setting up your Team for the first time, when you reach the section in the registration process asking if you want to Start a Team, Join a Team or Join as an Individual select “Start a Team”.)

Your WALK Team web page will be automatically created. When a participant registers online their own personal WALK Participant web page is also automatically created. Edit your team and personal WALK web page to tell your story—add a personal photo, add your story, add why HA and its mission is important to you. Send emails to everyone you know. WALK participants have the choice of using HA’s email templates or you can write your own. Your WALK web page will keep track of your donations in real time.

SETTING UP YOUR TEAM PAGE

Once you complete registration, click on “Participant Center.” Here is where you can edit your personal and team pages. As the Team Captain, you can:

- 1 Add a team photo.
- 2 Add a touching story.
- 3 Add a note to your team members that will appear in their participant centers.
- 4 Track your team roster and send personal or group messages to your team.
- 5 Send an invitation email to potential team members, inviting them to register and join your team.

And there you go! You’re now on your way to building a strong team that will help you reach your team fundraising goal!

Welcome to Jo Jo’s Team’s WALK to End Hydrocephalus Team Page



Welcome to Our Team Page!

Please join our team and WALK with us to End Hydrocephalus! This event is very dear to our hearts as we are walking on behalf of Jordan and so many others who are living with hydrocephalus and the constant fear that their shunt could fail at any moment. As you may know, hydrocephalus is a life altering, life threatening condition, caused by an abnormal accumulation of cerebral spinal fluid, resulting in pressure on the brain. The most common treatment for this condition is brain surgery to implant a medical device called a shunt, which has a 50% failure rate in children within the first two years. A shunt is not a cure as its consistent failures lead to multiple brain surgeries over a patient’s lifetime, in some cases 100 or more. This is unacceptable and this is WHY WE WALK. Please join our team, donate and help us reach our goal. Your donation is greatly appreciated and will go far in helping us find a cure and improve the lives of people living with hydrocephalus.

Thank you!

TOP TIP

Give your team a name—it can be as simple as the Smith Family Team or more original.

TOP TIP

The first participant to “start a team” automatically becomes that team’s Team Captain. If you choose not to serve as the team’s captain contact HA at walk@hydroassoc.org and the staff can change the person serving as Team Captain or assign Co-Captains.

USE THE EMAIL CENTER

There are also tabs at the top to assist you with the other functions of your HA WALK web page. Use the “Email” tab to enter your address book and send an email to everyone you know—you may use one of HA’s pre-written templates, edit one of HA’s templates or write your own! Again, experienced WALK participants report that sharing their personal story, their connection to hydrocephalus, is one of the most effective techniques. Every email automatically includes a hyper link to your personal and team web pages.

MAKE YOUR PERSONAL GIFT:

During registration you have an opportunity to make your own contribution first! Remember, all of your team members will follow your example.

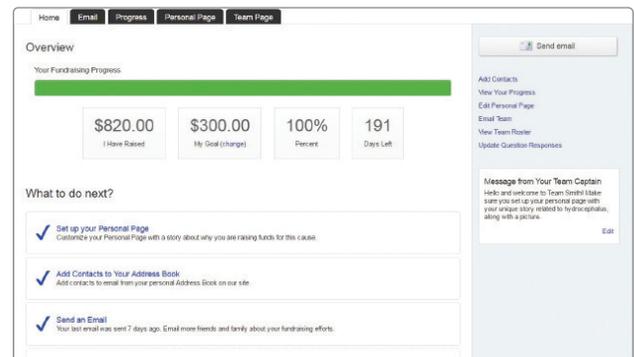


TOP TIP

You can login to your WALK web page at any time in the future by going to the WALK site web page and selecting “Participant Center” at the top of the main WALK web page.



Finish Registration by customizing your personal and team web pages from your participant center.



FACTS ABOUT HYDROCEPHALUS AND HA ACCOMPLISHMENTS

HYDROCEPHALUS

- Hydrocephalus is a chronic condition caused by an abnormal accumulation of cerebral spinal fluid, resulting in pressure on the brain.

HYDROCEPHALUS IS COMMON

- Over one million Americans have hydrocephalus, in every stage of life, from infants to the elderly. Head injuries causing hydrocephalus, including in our returning military personnel serving in Iraq and Afghanistan, are increasing the numbers of Americans living with this challenging condition.
- Anyone, at any age, may be diagnosed with hydrocephalus.
- Almost 8,000 babies are born with hydrocephalus every year.

THERE IS NO CURE

- Currently there is no prevention for hydrocephalus—there is no cure.
- The only treatment requires brain surgery, most commonly to implant a shunt to drain fluid from the brain. While shunts are life-saving devices for patients, complications resulting in multiple surgeries are common, particularly in pediatric patients.
- While many people are helped by surgery, many more need further operations to stay well. Having a shunt may require enduring multiple brain surgeries throughout the patient's lifetime—dozens of surgeries for a single patient are common, 100+ is not unheard of.

- The medical costs of treating hydrocephalus are over \$1 billion per year, yet in 2016, government funding of hydrocephalus research totaled \$6 million.

THERE IS A CRISIS IN DIAGNOSIS

- An estimated 700,000 older Americans have normal pressure hydrocephalus (NPH)—as many as 250,000 misdiagnosed as Alzheimer's, Parkinson's or dementia. If properly diagnosed and treated, many patients often return to normal functioning.
- Hydrocephalus often is undiagnosed and untreated in younger adults, leading to substantial loss of productivity and increased healthcare costs.

MORE EFFECTIVE TREATMENT IS NEEDED NOW

- In the past 50 years, although the device technology has improved, there has been no significant progress in the treatment methods for hydrocephalus.
- Research is essential. In the five years since the Hydrocephalus Association added "funding research" to its portfolio, it has committed more than \$5 million to research, making it the largest non-profit, non-governmental funder of hydrocephalus research in the U.S.! But new revenue resources must be found to continue HA's aggressive research program.

FACTS ABOUT HYDROCEPHALUS AND HA ACCOMPLISHMENTS (cont.)

THE HYDROCEPHALUS ASSOCIATION AND ITS ACCOMPLISHMENTS

- The Hydrocephalus Association was founded in 1983. It is the largest non-profit organization dedicated solely to hydrocephalus. Its mission: to find a cure for hydrocephalus and improve the lives of those affected by the condition.
 - HA provides superior program services (support and education) including:
 - One-on-one support—support and education for the newly diagnosed as well as patients and families facing new or ongoing challenges
 - Sponsoring biennial conferences for patients and their families
 - Annual scholarships for high school students with hydrocephalus pursuing higher education.
 - Writing, editing and revising more than 25 hydrocephalus-related publications (brochures, booklets, brochures and fact sheets) distributed to the hydrocephalus community, the public, medical professionals and medical facilities.
 - Sponsoring 41 Community Networks (formerly called support groups) in 26 states.
 - Developing and maintaining the Hydrocephalus Resource Library, an online, searchable database of specialized information about hydrocephalus.
 - Developing and maintaining a directory of neurosurgeons and physicians treating hydrocephalus across the U.S.
 - Publishing a monthly e-newsletter (quarterly paper version) distributed to patients, families and medical professionals
 - Organizing and coordinating grassroots lobbying efforts to increase federal funding of hydrocephalus research
 - In addition, HA is funding research—basic, clinical and translational. Research that benefits those living with hydrocephalus today as well as working toward a cure.
 - HA research is already paying dividends. The HCRN (Hydrocephalus Clinical Research Network), an HA funded initiative, has developed a protocol, which when followed by hospitals and medical centers, can reduce the incidence of shunt infections by 34%.
 - Current research for pediatric hydrocephalus includes:
 - Data Projects
 - Characterizing Patient Populations
 - Shunt Infection Registry
 - ETV Registry
 - Determining when ETV and ETV-CPC are appropriate
 - Understanding if ventricular size affects cognitive outcomes
 - Finding biomarkers for post-hemorrhagic hydrocephalus
- While hydrocephalus is often associated with newborns and infants, it also frequently affects older people—a condition called Normal Pressure Hydrocephalus (NPH.) Unfortunately NPH is often undiagnosed, misdiagnosed or untreated—typically confused with Alzheimer’s, Parkinson’s and/or dementia. HA has formed



a special research division especially for adults living with hydrocephalus—the Adult Hydrocephalus Clinical Research Network (AHCNRN). Current research in this area includes:

- Core Data Projects
- Characterizing Patient Populations
- Imaging database
- CSF Biobank
- Improving the outcomes for transition, arrested, acquired and NPH patients.
- Understanding the natural history and treatment responses.
- Reducing complication associated with shunts and ETVs (endoscopic third ventriculostomy).

HA is the largest non-profit private funder of hydrocephalus research in the U.S. But there so much more research that could be funded with more resources. Current research projects of interest:

- A Nasal Spray to Increase CSF Absorption
- Ventricular Repair and Recovery
- Preventing Post-hemorrhagic Hydrocephalus
- Biomarkers for Post-hemorrhagic

Hydrocephalus

- Targeted Therapies for Congenital Hydrocephalus
- Brain Cell Reaction and Recovery Under Pressure

All of this and more is possible because of the funds raised with HA WALKs to End Hydrocephalus!

Every walker raising money is making a significant difference in the lives of those living with hydrocephalus and the future patients.

Hydrocephalus Association is a registered 501(c)(3) non-profit organization—Tax ID: 94-3000301

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