STATISTICS HAVE SHOWN THAT FAMILY TEAMS USING “LETTER WRITING CAMPAIGNS” TO RAISE MONEY FOR THE WALK TO END HYDROCEPHALUS HAVE A MUCH HIGHER “PER TEAM” DOLLAR AVERAGE THAN FAMILIES USING OTHER METHODS OF RAISING MONEY. WE ENCOURAGE ALL PARTICIPATING FAMILY TEAMS TO TRY A LETTER WRITING CAMPAIGN AS WELL AS RAISING MONEY “IN PERSON,” FOR THE BEST OF BOTH METHODS. LETTERS MAY BE SENT VIA U.S. POSTAL SERVICE, VIA EMAIL OR BOTH.

(IF SENDING A HARD COPY LETTER ENCLOSING A SELF-ADDRESSED ENVELOPE WILL INCREASE YOUR RESPONSE RATE.)

LETTER WRITING CAMPAIGNS ALSO HAVE ANOTHER, VERY IMPORTANT, PURPOSE – IN ADDITION TO ASKING FAMILY MEMBERS AND FRIENDS TO SPONSOR YOUR TEAM’S PARTICIPATION IN THE WALK TO END HYDROCEPHALUS, THEY HELP INCREASE PUBLIC EDUCATION AND AWARENESS ABOUT HYDROCEPHALUS AND ITS CHALLENGES – A VERY IMPORTANT GOAL IN MAXIMIZING HA’S POTENTIAL. NEED ASSISTANCE OR MORE INFORMATION ABOUT CONDUCTING A LETTER WRITING CAMPAIGN? PLEASE CONTACT THE HA OFFICE – WALK@HYDROASSOC.ORG SAMPLE LETTER #1

RAISING MONEY WITH A LETTER WRITING CAMPAIGN

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. (Sample letters are below.)

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
Mail and/or Email 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

Mail or email your letters, ideally eight weeks before the WALK to End Hydrocephalus. But if you’re running late don’t despair, there’s still time – you have until 4 weeks after the event to finish collecting money.
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.

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**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
**Facts about Hydrocephalus**

**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. Many US military personnel who suffered traumatic brain injury during service in Iraq and Afghanistan are developing hydrocephalus as a result.
- Anyone, at any age, may be diagnosed with hydrocephalus.
- Almost 8,000 babies are born with hydrocephalus every year.
- Hydrocephalus is the most common reason for brain surgery in children.

**There Is No Cure**
- Currently there is no prevention for hydrocephalus—and there is no cure.
- The most common treatment is brain surgery to implant a shunt—but a shunt is not a cure! A shunt is only a control—and in children has a 50% failure rate in the first two years, requiring additional surgeries.
- While many people are helped by surgery, many more need further operations to stay well. Over 40,000 hydrocephalus operations are performed annually in the U.S. (one every 15 minutes.). Having a shunt may result in a single patient enduring dozens of brain surgeries just to survive; a single patient undergoing 100+ is not rare.
- The medical costs of treating hydrocephalus are over $1 billion per year, yet in 2016 government funding of hydrocephalus research totaled less than $6 million.

**There Is a Crisis in Diagnosis**
- An estimated 700,000 older Americans have normal pressure hydrocephalus (NPH)—as many as 250,000 may be misdiagnosed as Alzheimer’s, Parkinson’s disease or dementia. Sadly, many are living in nursing homes unnecessarily—when properly diagnosed and treated the patient often returns to normal functioning.
- Hydrocephalus often is undiagnosed and untreated in younger adults, leading to substantial loss of productivity and increased health-care costs.

**More Effective Treatment Is Needed Now**
- In the past 50 years, although the technology has improved, there has been no significant progress in the treatment methods for hydrocephalus.
- Research is essential. Since 2010 when 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.

**The Hydrocephalus Association (HA)**
- The Hydrocephalus Association was founded in 1983. It is the largest non-profit organization dedicated solely to hydrocephalus in the world. Its mission: to promote a cure for hydrocephalus and improve the lives of those affected by the condition. You can help. Join the Hydrocephalus Association now in their fight against hydrocephalus!
SAMPLE LETTER #1

The Rodger Family
Street Address
City, State Zip Code

Date

Dear Team Alex Members,

I have decided that since I am 12, and heading into 7th grade in a few weeks, maybe it should be my turn to write this year’s WALK letter!

I hope everyone is having fun this summer. My summer has been great; baseball camp, band camp, a trip to Atlanta with my Dad to see the Braves play (an incentive trip for getting all A's on my report card!) and a relaxing trip to Sanibel. I am looking forward to starting my 2nd year in the Pre Med Academy at Boca Raton Middle School; continue to play the trumpet in Band, and moving to the next level of baseball in Boca Raton Little League.

The South Florida WALK to End Hydrocephalus is Saturday, November 9, 2013 at Quiet Waters Park (Shelter #10) in Deerfield Beach. Last year’s WALK was the biggest and best ever! My Mom and Dad (with our family and friends) worked really hard to raise a lot of money and with the help of all the other teams; we raised over $57,000 (That was $7,000 over our goal!)

In the next few months, I will work hard to raise Hydrocephalus awareness. It is important that more people know about it for change to happen. My Mom says there are too many shunt surgeries happening and more research is needed. I have been really lucky that I haven’t needed surgery in four years; I hope I never have to have one ever again. (I have had 7 already!) The WALK is also important to me because it is a chance for people to come together as one. I want other families affected by this condition to know that they don’t have to be labeled by it. Anything is possible. We have 20 teams registered and almost $17,000 raised so far. I know we can reach our new goal!

Please help me support the Hydrocephalus Association and people like myself! You can:

1. Join us at the WALK on Saturday, November 9th at 9 am as a Family Team, a Corporate Team, an individual walker or a “virtual walker” Please remember to register on our website.

2. If you are unable to be at the WALK to End Hydrocephalus but would like to donate, you can simply use the enclosed envelope (please make all checks payable to the HYDROCEPHALUS ASSOCIATION with Team Alex in the memo) Our address is: XXXXXXXXXXXXXXXX

3. You can donate directly to Team Alex on line on our website insert URL to WALK Team or Participant Page

4. You can encourage your company and/or local businesses to become corporate sponsors by donating either monetarily or in kind (food, water, prizes for our raffle.)

5. Learn more about Hydrocephalus (www.hydroassoc.org) and help spread the word!

If there are any questions, please feel free to contact my Mom, Eileen Rodger at insert Team Captain's email address or at XXX-XXX-XXXX.

All donations are gratefully accepted and tax deductible. (Tax ID#: 94-3000301)

Thank you and hope to see you there!

Alex (Michael and Eileen) Rodger
SAMPLE LETTER #2

The Harris Family
Street Address
City, State, Zip Code

Dear Friends and Colleagues,

It’s hard to believe but it was more than 13 years ago when we sat with a pediatric neurosurgeon looking at CT scans of our newborn baby’s head, as he explained that he had a condition called hydrocephalus. At the time, I didn’t even know how to pronounce it, or that people even have ventricles (spaces filled with cerebral fluid) in their brains. We were told that his condition was “incompatible with long term survival” and that it would be fatal if we did not act quickly. The doctor told us, that there is no cure but that he could possibly save our son’s life, his sight, his hearing and his mental abilities by operating to place a shunt into his brain. The shock of that moment with some hope that there is treatment caused us to look past an important point….“there is no cure”.

As most of you know we have been blessed. The shunt has worked so well for Joey that we sometimes forget that it is just a temporary treatment and that there is no cure. In January of this year however, we were again reminded that there is no cure, when Joey’s shunt suddenly failed again. In an instant we were back to where we were 13 years ago… where we will probably be again at some time in the future.

While we continue to be grateful for the many doctors, nurses and bioengineers that have helped Joey, there still is no cure for hydrocephalus. The shunt is at best a temporary treatment for life threatening condition that requires numerous unplanned brain surgeries to stay well. Joey has had 9 surgeries since his first. We also know that Joey is fortunate. So many others with hydrocephalus that we have come to know, have dealt with so much more than he has. With a little more research we may be able to change this. That is why this year we are walking again to raise money and awareness for the Hydrocephalus Association; especially for those who have it worse than Joey, because there is no cure….and there should be.

We are very excited that the WALK to End Hydrocephalus will be held at the Chicago lake front. Please come walk with us on September 14 at 9:30 AM on the lake front at Soldier’s Field in Chicago. To join or sponsor Team Harris, for the Chicago WALK to End Hydrocephalus, follow this link (insert link to WALK team’s web page) to visit our team web page. Some email systems do not support the use of links and therefore this link may not appear to work so you may copy and paste the following into your browser:

Joey Harris Personal WALK to End Hydrocephalus Page Link: insert entire URL for team’s web page

If you’re receiving this letter in the mail you can type the address above into your web browser, too. Or, if you prefer you can send us a check made payable to the Hydrocephalus Association. Thank you for your support – for Joey and all of those living with the challenges of hydrocephalus.

Tim, MaryBeth, Tim, Terry, Brian and Joey Harris
Hello Family and Friends,

Do you know that more than 6,000 babies born this year will face a lifetime with the challenges of hydrocephalus? And that hydrocephalus is number one reason for brain surgery among children? That anyone, at any time can be diagnosed with hydrocephalus? At this time there is no prevention and there is no cure.

When Amy was diagnosed with hydrocephalus – an abnormal accumulation of cerebral spinal fluid in the brain - at 2 days old, Janice and I were terrified! We had no idea what hydrocephalus was and what sort of future our daughter faced. The first 10 weeks of Amy’s life were “touch and go” with every day bringing a new challenge including multiple surgeries on our tiny, fragile baby. Although the doctors and nurses performed heroically during that time, we felt very alone. We never would have made it without the love and caring of family and friends like you …and the information and support we received from the Hydrocephalus Association (HA).

If you are unfamiliar with the organization, the stated mission of the Hydrocephalus Association is “to promote a cure for hydrocephalus and improve the lives of those affected by the condition." Currently Amy is doing so well --- to date she hasn’t shown any signs of developmental delay. And she hasn’t suffered any problems with her shunt this year – we had one serious scare a few months ago but, thankfully, it turned out to be a virus. (The symptoms of shunt malfunction mimic the flu or other diseases – while the flu isn’t great it’s infinitely preferable to a shunt infection or shunt malfunction!) Unfortunately, hydrocephalus is only controlled – not cured – and life-threatening complications can develop in a heartbeat, keeping us extremely watchful for the tiniest change in her behavior.

In 2009, the Hydrocephalus Association added “funding research” to its mission, to learn more about this chronic and challenging condition. Since then HA has committed over $5 million to research – making it the largest non-profit, non-governmental funder of hydrocephalus research in the U.S. That is why Janice, Amy and I will again be participating in the HA WALK on October 21 here in Raleigh, NC. Last year our team, Amy’s Army, raised over $1,270 thanks to your support! We were incredibly gratified by the generosity shown by our family and friends and very appreciative of your support. Thank you so much. Our goal for this year is $1,600 and we hope that you will, once again, support us team with a tax-deductible contribution. Donations of any size are gratefully received.

For obvious reasons we feel this is a very worthwhile cause. Your donation will support critical research and program services so that our daughter, and more than one million other Americans living with the challenges of this complicated and complex condition, can lead a better life.

You can track our progress – and donate – online at insert URL for team’s WALK web page. It’s quick and easy! Donations may also be directly mailed to us at 472 Walters Street, Raleigh, NC 27655. Please send all donations by the end of October and make all checks payable to the Hydrocephalus Association.

Thank you for being a part of our lives! Your support and love makes the difference.

Much love and gratitude,

John, Janice and Amy
Amy’s Army

P.S. Please feel free to e-mail or forward this message to anyone! The more people who know about hydrocephalus, the better!
SAMPLE LETTER #4

The Capalet Family
888 New York Avenue
Durham, NC 28653

Dear Family and Friends,

Do you know that there are over 1 million Americans living with hydrocephalus and there is no cure? That anyone, at any age, can be diagnosed with hydrocephalus? (I can testify to that!) The most common treatment is brain surgery to implant a shunt – but a shunt is not a cure and shunts have a poor track record frequently malfunctioning and requiring additional brain surgeries to fix or replace them.

If you don’t know the whole story about 3 years ago I began to feel “dull” – my mind just wasn’t as sharp as usual. I brushed it off as “getting older.” But then I noticed problems with my balance – I became clumsy – I couldn’t seem to pick my feet up! After weeks of seeing doctors and multiple tests (some doctors said it was Alzheimer’s, some said Parkinson’s – others said it was dementia – all of which were terrifying) I was finally, correctly diagnosed with Normal Pressure Hydrocephalus (an excess accumulation of cerebral spinal fluid in the brain). Cindy and I were devastated. We didn’t know what this diagnosis meant, how it would affect our lives, and feared it would wreak havoc on our family and future. It was a hard time…made easier by the tremendous love and support of our family and friends like you. But it would have been so much more difficult without the Hydrocephalus Association (HA) – and the information and support it provided. (Although there is a lot about hydrocephalus on the Internet -- much of it misinformation I later learned – most of it didn’t seem to apply to me.) The HA staff was terrific at explaining my condition and allaying many of our fears.

I am doing pretty well – shunts work much better in adults than in children. When I was first diagnosed I was shocked to learn that there have been no significant developments in hydrocephalus treatment methods since the development of the shunt 50 years ago – back when I was in grade school! Hydrocephalus research hasn’t received much government funding either – last year the US government invested a paltry $6.2 million on it – even though more than one million Americans are affected by the condition.

Cindy and I are grateful for every day without any of the numerous complications that affect so many people with hydrocephalus. I have also been incredibly fortunate to have a great family and friends who have helped surmount the challenges of living with this condition – but it takes an enormous toll on the entire family. Cindy and I now participate in a local HA Community Network. We truly believe that HA is our best hope for finding a cure. It is the largest non-profit, non-governmental funder of hydrocephalus research in the U.S. HA’s mission is “to promote a cure for hydrocephalus and improve the lives of those affected by the condition.” But research is expensive and finding new resources to fund this vital research is critical.

This is why our family will be participating in the WALK to End Hydrocephalus again this year. Last year, due to the generosity and support of our fabulous family and friends, our WALK team – Pacin’ for Jason – raised $875! We are so grateful for your support. We are hoping you will consider making a tax-deductible donation to support our team in this year’s WALK (scheduled for October 14th here in Durham) so the Hydrocephalus Association can continue to advance its research initiative.

As you can imagine, we feel this is a very worthwhile cause and we plan to participate annually until there’s no longer a need. We’ve set a goal of $1,000 this year – with your help we can reach that goal. Any amount you can contribute is very much appreciated. The dozens of WALK to Cure Hydrocephalus events across the U.S. are totally volunteer initiated and coordinated – making them very cost effective and maximizing the amount of money that can be used for the mission.

Making a donation with a credit card on our Team web page is fast and easy. Go to: [insert URL for Team’s web page]. Or mail your contributions to us at 888 New York Ave., Durham, NC 28653. Please send any contributions by mid-November and make all checks payable to...
the Hydrocephalus Association. If you’re unable to donate this year we hope you’ll keep us in your thoughts and prayers. Or join us and walk with us (and raise money from your family and friends!) Please stay in touch–our email address is: thecapalets@gmail.com. Thank you for your support and being a part of our lives!

Much love,

Jason, Cindy, Max and Judith

P.S. Please feel free to forward this letter to anyone – the more people who know about hydrocephalus the better!