Hydrocephalus Association

Letter Writing Campaign

Follow these simple steps to create your own letter writing campaign and reach your fundraising goal. Make sure you register first and take a look at the Participant Center for a few sample templates that can be copied into your own Word document to print and mail.

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) –

- Sign each letter individually; perhaps with a personal closing.
- Make sure to leave the signature block blank so you can personally sign each letter.
- 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

Clubs, organizations, teams 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, there’s still time – you have 4 weeks after the WALK to finish collecting money toward a recognition gift.

4. Collect Your Donations – Nothing is quite as exciting as receiving your mail or checking your WALK 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!

5. Attend the WALK to End Hydrocephalus – Have fun! Join your teammates and others who are walking to make a difference! Take a great thank you photo!

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 team raised. Consider printing your best team photo to say thank you and share the day with your donors.

Facts about hydrocephalus

Hydrocephalus

Hydrocephalus is a chronic condition caused by an abnormal accumulation of cerebrospinal 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.
- Over 5,000 babies are born with hydrocephalus every year in the US alone.
- 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 36,000 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 hospital charges for hydrocephalus are over $2 billion per year, yet the National Institutes of Health (NIH) invests less than $11 million per year in hydrocephalus treatment.

There Is a Crisis in Diagnosis

An estimated 800,000 older Americans have normal pressure hydrocephalus (NPH) – as many as 640,000 of them are undiagnosed or may be misdiagnosed with 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 healthcare costs.

More Effective Treatment Is Needed Now

Over the last 65 years, although technology has improved, there has been no significant change in hydrocephalus treatment.

Research is essential. Since 2009 when the Hydrocephalus Association added “funding research” to its portfolio it has committed more than $13.8 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 impacted by the condition. You can help. Join the Hydrocephalus Association now in their fight against hydrocephalus!

Letter Writing Campaign (Cont.)

SAMPLE LETTER #1 (Returning Team)

The Rodger Family
Streeet Address
City, State Zip Code

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 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: insert your address.

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 insert phone number. 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

Letter Writing Campaign (Cont.)

SAMPLE LETTER #2

The Harris Family
Streeet 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 a 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

Letter Writing Campaign (Cont.)

SAMPLE LETTER #3

Jones Family
Streeet Address
City, State Zip Code

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 the 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 "find a cure for hydrocephalus and improve the lives of those impacted 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.

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 our 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 insert address. 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 email or forward this message to anyone! The more people who know about hydrocephalus, the better!