

THE HYDROCEPHALUS ASSOCIATION

*"In a sea of **hopelessness**, you were our buoy.*

*When we felt we had **no one**...*

your phone number was our only

***connection to hope**".*

Friday, November 11, 2005

Dear {first name},

At times, each of us stands breathlessly on the threshold of an unforgettable moment that has the power to radically change our lives - for better or worse.

No doubt, such life altering experiences are not news to you. For myself, well, as President of the Board of Directors, I hear about them almost daily.

I'd like to share one such moment with you...

Angela Batterman lay peacefully in a dimly lit hospital room on October 12, 2002. The clock on the wall could be faintly heard ticking away the seconds of the early morning hours.

But, for Angela, time seemed to stand still as gentle tears of joy slowly rolled down her cheeks.

You see, a few hours earlier she had crossed one of those magical thresholds of life as she brought a fresh, bright, new child into the world... it was their first baby... a boy they named Joseph.

The Painful Terror of the Unknown

But you and I know both know that life is not all full of roses and butterflies. And not all life-changing moments bring tears of joy.

14 months had passed since that bright October morning. Angela and her husband Chris sat together once again in a medical facility.

One-year old Joseph sat quietly on their lap. Anxiously, this small family waited for the results of CT scan Joseph had been given a few days earlier. It was the second scan in the past 3 months... a "second" opinion if you will.

With little fanfare the doctor sat down and pronounced a single word - "**Hydrocephalus**".

Over, please...

There is a terror in that word... the horrible terror of the unknown. It is not like hearing words like "cancer", or "down syndrome" or "diabetes" - scary words to be sure, but words that are a known danger.

Think about it - with hydrocephalus, so little is known and so few doctors really specialize in treating it.

Indeed, had Joseph's first neurosurgeon only known what to look for, the past 9 months would have been so much different...

A Christmas Eve Never to be Forgotten

It was Christmas Eve 2002. The sweet spirit of Christmas that lingered in Chris and Angela's home was shattered as tiny 2-month old Joseph went into a full seizure. Without delay, he was frantically rushed to the hospital.

Now, you and I know that major seizures don't typically happen in infants. However, after a few hours in the ER and some tests, the Batterman family was sent home. "He'll be just fine."

But he was not "just fine". Choking on the softest solid foods was a constant experience - so much so that he lived on pureed food until he was 14 months.

Normal crawling was never experienced. Walking came with profound difficulty. And when he did finally get his feet under him, he was as wobbly as a drunken sailor, often falling flat on his face... his tiny arms never reaching out to stop the fall.

For Angela and Chris, time stood still once again as they sat staring at the doctor that dark day. A million questions raced through their mind.

But there was little time for answers - Joseph needed emergency surgery. Seven days later the first VP shunt was put in place. Two more would follow.

Angela, Chris and Joseph had entered a new world. Where could they find answers, help, and a loving hand... a hand that understood the pain, the fear and the hopeless feeling that so often accompanies hydrocephalus?

A "Family" With Focus!

Eventually, after many tears and sleepless nights, the Batterman's found that loving hand.

As Angela says, "Through the support we received from the Hydrocephalus Association we found security... **and hope**. They are more than an awesome resource, they are an extension of our family."

Family - perhaps that best describes what we try to provide here at the Hydrocephalus Association.

You see, we have a passion for helping people with hydrocephalus and those that lovingly help them - whether it is parents, siblings, neighbors, or medical professionals.

Reaching out to people is what we are all about. We have accomplished so much over the past 22 years!

In 1983, when the Association was founded, there were very few resources for people with hydrocephalus and their families

But, today, the Association has created a wonderful "family" and empowered them with resources and services like...

- **Newsletter:** A quarterly newsletter that publishes a wide variety of information ranging from details on the latest research and surgical procedures to support network information.
- **Information Packets and a DVD:** Numerous information packets covering every age and stage of Hydrocephalus. We have provided these FREE of cost to tens of thousands of people nationwide.
- **The "LINK" Support Network:** An unparalleled group of more than 1,300 "family" members ready to love, support, and educate.
- **One-on-One Strength:** Every day our trained specialists are available - FREE of charge - to answer questions, give guidance... or just to listen.
- **Group Events:** Our "TEAM" events gather people from Florida to California to support each other and the Association. *It's a powerful way to share warm smiles, build memories, help shoulder each other's burdens and help the Association.*

These resources have made a **big difference** in the lives of so many people. Perhaps they have made a difference in your life?

Changing Lives... Bringing Hope

I know they have for Cindy Hirsch. Her story, like little Joseph's, is full of life-changing, magic moments...

"After I was diagnosed at the age of 40, the Hydrocephalus Association allowed me to better understand my condition. Through LINK, I was able to gain friendships with many new people - people that listen and understand when I need to talk about being a wife and a mom with hydrocephalus."

So you see, we have come a long way. But clearly, we are not there yet. We are determined to continue moving forward.

Over, please...

That inexhaustible determination led us to organize the first ever National Institute of Health (NIH) sponsored workshop that focused exclusively on hydrocephalus. This historic event, held just this past September, brought together an unparalleled number of doctors, researchers, patient advocates, government directors, and families.

This and other events have helped us define extremely ambitious - **but very attainable** - goals for the coming months and years. Consider a few of them...

- ✓ **Increase Knowledge** - We will actively confront the lack of basic knowledge about how hydrocephalus affects the brain by actively promoting interdisciplinary research.
- ✓ **More Funding** - We will aggressively petition Congress to encourage significant NIH funding of hydrocephalus research.
- ✓ **Improved Programs** - We will move forward as never before to expand our programs and improve our services.
- ✓ **Local Groups** - We will embark on an initiative to launch local support groups and increase TEAM meetings around the country.
- ✓ **The Rising Generation** - We will continue to attend to the needs of families with children and of older adults with NPH. Additionally, we will place a priority emphasis on better serving and understanding the first generation of youth who were successfully treated for hydrocephalus as children.

Just imagine how many lives will be touched and improved when we combine these accomplishments with our current line-up of services. It is inspiring!

You Hold the Power of Hope in Your Hands

But I must give you this one word of caution:
We simply cannot do it alone.

However, with your help, we are sure to see these things accomplished... and many more!

Today, more than ever, people like little Joseph and Cindy need the Hydrocephalus Association and the resources we offer. More than that, each year thousands of infants, children, teens and adults are diagnosed with hydrocephalus.

They and their loved ones are sure to find themselves in a world filled with the terror of the unknown. Many will be hopeless, alone and scared about what the future may hold.

Take a look at the reply card and envelope I have enclosed. When combined with your most generous gift of \$35, \$50, \$75, \$100 or more, they represent the sweet gifts of comfort and hope!

Next page, please...

That's right. In your hands you hold the opportunity to truly bless the lives of thousands of people. Only with gifts like yours will our dreams of service actually become reality.

So, please give the gift of hope today.

They Are Standing at the Threshold - Will You Help Them?

Today, little Joseph is 3 years old. Recently, Angela and Chris stood on the sidelines at a kickball game. With gentle tears of joy once more streaming down her face, Angela manned a digital camera as best she could.

With the other children, Joseph raced around the field, strong and steady. He had come a long way since the days of falling flat on his face.

But, more than having balance and strength today, the Batterman's have hope.

Right now, today, thousands of individuals stand breathlessly waiting on one of those special thresholds of life. Take a minute - while it is still handy - to return a gift of \$35, \$50, \$75, \$100 or more.

It is a gift that will ensure that peace, joy, and hope await them on the other side of that threshold.

Sincerely,

Russell Fudge
President of the Board of Director

P.S. **I almost forgot to tell you...** not only will your financial gift bless the lives of people today, it will also have a powerful influence on members of Congress as they deliberate on whether or not to support hydrocephalus research. You see, your donation is a cry of support and a demand for better research. So please, return your gift today - the impact will be immeasurable!