

## Dear Friends of the Foundation,

### 2007 ANNUAL APPEAL

Our sensational sixth year is off to a roaring start and it's all because of you—our amazing supporters! We thank you all from the bottom of our hearts for your continued and generous financial support and volunteer efforts.



Zach & Benji

As we do each and every year, we kicked off this year with our annual appeal, and to date we have received \$3,645. Thank you to everyone who has already donated. Our ultimate annual appeal goal is to raise \$100,000. This goal seemed unattainable until we looked at it in smaller increments; if we received 1,000 donations of only \$100 we could reach our goal. The funds from the annual appeal combined with the funds raised during our events could bring our fundraising to record levels. Please use the enclosed envelope to make your annual donation (cash, check and credit cards are now accepted) or visit our website at [www.onesmallvoicefoundation.org](http://www.onesmallvoicefoundation.org) and click on the "Donate Now" button. Thank you in advance for your continued support. Our voice is being heard as a result of your support.

The One Small Voice Foundation is very literally "one small voice" striving to make a difference in the lives of children and their families with the syndrome of optic nerve hypoplasia and hydrocephalus. We are supporting very amazing research being conducted at Children's Memorial Hospital Chicago, Children's Hospital Los Angeles and the Hydrocephalus Association. The doctors and researchers at these fine organizations work tirelessly to improve the quality of care and find the cause of these life-threatening diseases. We have included in this newsletter updates from the three teams of researchers we are supporting and we have even more detailed information available on our website.

In addition to the very exciting updates from our research teams, we have an update from Zach's Mom, information about upcoming events, definitions of the diseases, a synopsis of the 3rd Annual Open Toe Shoe Party, a photo gallery of 2006-07 events, winners of the 2006 and 2007 Zach Award, other ways to donate, a special thank you to our supporters and corporate sponsors and more...

We hope you enjoy the newsletter, we look forward to seeing you at events this year and we thank you for your ongoing support.

Peace and blessings,

Debbie, Kevin, Zachary and Benjamin Katzbeck and  
The One Small Voice Foundation Board of Directors

### 2007 DISBURSEMENT REPORT

The foundation is just about to close its 7th fiscal year in August and we are pleased to announce that since our inception (August 2000) the foundation has donated \$250,729.36 to research/education. The primary recipients were the Hydrocephalus Association, Children's Hospital Los Angeles and Children's Memorial Hospital Chicago for their important research of Hydrocephalus and Optic Nerve Hypoplasia.

Your generous donations combined with the fact that no one in the foundation accepts a salary, plus the generosity of our corporate sponsors (The Orion Group and its business partners: ZGraphics, Genesis Press, Mallard Press and Vision Mailing Services); nearly 100% of funds raised goes to research.

The donations were distributed as follows:

- Children's Hospital Los Angeles: 169,329.36
- Children's Memorial Chicago: \$61,300
- Hydrocephalus Association: \$16,600
- The Guild for the Blind: \$3,500

Thank you all for your continued support. If it were not for your generosity we could not continue to make these amazing donation milestones.

### WHAT IS HYDROCEPHALUS?

Hydrocephalus comes from the Greek: "hydro" meaning water, "cephalus" meaning head. Hydrocephalus is an abnormal accumulation of cerebrospinal fluid (CSF) within cavities called ventricles inside the brain. CSF is produced in the ventricles, circulates through the ventricular system and is absorbed into the bloodstream. CSF is in constant circulation and has many important functions. It surrounds the brain and spinal cord and acts as a protective cushion against injury. CSF contains nutrients and proteins necessary for the nourishment and normal function of the brain. It also carries waste products away from surrounding tissues. Hydrocephalus occurs when there is an imbalance between the amount of CSF that is produced and the rate at which it is absorbed. As the CSF builds up, it causes the ventricles to enlarge and the pressure inside the head to increase.

Hydrocephalus that is congenital (present at birth) is thought to be caused by a complex interaction of environmental and perhaps genetic factors. Aqueductal stenosis and spina bifida are two examples. Acquired hydrocephalus may result from intraventricular hemorrhage, meningitis, head trauma, tumors and cysts. Hydrocephalus is believed to occur in about 2 out of 1,000 births. The incidence of adult-onset hydrocephalus and acquired hydrocephalus are not known.

### HOW IS HYDROCEPHALUS TREATED?

There is no known way to prevent or cure hydrocephalus. The most effective treatment is surgical insertion of a shunt (most drain from the brain into the stomach or heart). Endoscopic third ventriculostomy (ETV) is growing in popularity as an alternative treatment method for hydrocephalus; unfortunately, it cannot be used for all patients.

This definition was taken from the Hydrocephalus Association website ([www.hydroassoc.org](http://www.hydroassoc.org)). If you have hydrocephalus or are a parent of a child with hydrocephalus please go to the website and register in the research database.



Sleepy Zach finds comfort in Dad's arms at the Open Toe Shoe Party.

Continued on inside...

# Updates from the Desk of...

## DEBBIE KATZBECK

Founder/President/Zachary's Mom  
One Small Voice Foundation

### An Update on Zachary's Progress



Since our last newsletter Zachary has continued to battle with his medical conditions. We have had two shunt malfunctions and surgical revisions, only a few seizures (thank you, God) and, unfortunately, we have had over 12 hospitalizations for cortisol crises related to various infections. A cortisol crisis occurs when there is stress on the body caused by an infection, seizure or shunt malfunction. Zachary's body

is missing ACTH, which tells his body to produce cortisol in times of positive and negative stress. Zachary's crises are getting progressively more severe and life threatening. We are seeing a dramatic and dangerous drop in Zachary's heart rate, which doctors believe is caused by his brain forgetting to tell his heart to keep beating during these crises. We are working with our team to try and determine a new plan of action as Zach is not responding to the current course of treatment. He is remaining unconscious for longer periods of time and requiring more medical

intervention. These episodes are frightening for all of us—not just Mom and Dad, but little brother Benji too! Benji is a champion little brother who stays by Zach's side and visits him in the hospital.

When Zachary was born we thought his vision impairment and global developmental delays were going to be our biggest challenge. We now know keeping him alive is our biggest challenge. It fuels our drive to continue fundraising.

Outside of the medical world, Zachary is now 7½ years old and brother Benji is 5 years old. Zachary will be starting second grade and Benji will be starting kindergarten in the fall. Zachary is still busy with physical therapy, speech therapy, occupational therapy, therapeutic horseback riding, swimming and VIP soccer. He LOVES his little brother and his little brother loves him. We have two amazing little boys and the support of many caring family members and friends who are helping us help Zachary achieve more than we ever imagined. Keep checking our website throughout the year for more updates on Zachary and his condition. 🍀

## DR. MARK BORCHERT, MD

Ophthalmology, Division Head

## CASSANDRA FINK, MPH

Clinical Research Coordinator

## PAMELA GARCIA-FILION, MPH

Clinical Research Associate

Childrens Hospital Los Angeles

### Regarding: Update on Optic Nerve Hypoplasia Research

The ONH research program at Childrens Hospital Los Angeles has evolved from a single study of children with ONH into a comprehensive research and social services center for children with ONH and their families. Our team of committed researchers and staff, coupled with the dedication of organizations like the One Small Voice Foundation, are working hard to identify prenatal risk factors and the clinical pathologies associated with ONH.

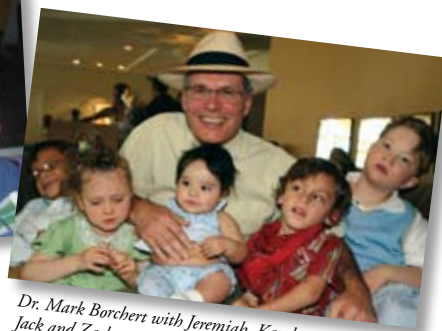
In the last year, two new areas of interest within our research were brought to our attention by parents of our patients. Both areas of study are very important because they greatly impact not only the child's quality of life, but also that of the entire family.

- **Sleep Dysfunction:** We were continuously hearing stories from parents frustrated by their child's irregular sleep pattern. After researching sleep dysfunction and ONH, we partnered with a pediatric endocrinologist who specializes in sleep disorders, Scott Rivkees, M.D. This collaboration produced a new study to determine the prevalence of sleep disorders in children with ONH by using a wristwatch that tracks when a child is asleep or awake. We anticipate preliminary findings by the end of the year.
- **Autism Spectrum Disorders:** Parents and caregivers of patients with ONH frequently report common behaviors, including: tactual defensiveness, rigid adherence to routine, developmental delays, repetitive behaviors and atypical language development such as echolalia. Within the next few months, we will begin to screen all subjects in our study for autism spectrum symptoms and disorders.

Finally, the big news is that we are in the process of publishing the results of our findings on developmental outcomes in children with ONH based on our first 73 completed subjects. We look forward to sharing our results with you in the near future. When the full article is available, you will be able to find it on the One Small Voice Foundation website.



Dr. Borchert & Zach



Dr. Mark Borchert with Jeremiah, Kambree, Hannah, Jack and Zachary

### Autism/Optic Nerve Hypoplasia Special Appeal Supplemental Funding Request

Optic nerve hypoplasia (ONH) is the congenital insufficiency of ganglion cells that normally form the optic nerves. While ONH primarily affects vision, secondary pathology involves endocrine dysfunction, brain malformations and developmental deficits. To date, we have analyzed the clinical risk factors for endocrinologic and developmental outcomes in young children with ONH. Analysis of ophthalmic findings and the association of vision outcomes with clinical characteristics cannot commence until baseline electrophysiologic data is processed. Currently there is a backlog of subject electrophysiology data and matching funds must be provided to our research collaborators at Glasgow University in Scotland before their research fellow can be assigned the project. We are requesting supplemental funding outside of the research monies raised for the daily operations of the ONH clinical study to support this project.

Monies donated will be used to support data processing and, indirectly, will aid the refinement of clinical testing protocols.

Specifically, data processing will provide data on ganglion cell function which, combined with vision and fundus data, may improve the prognostic value of electrophysiologic testing in infants with ONH. Moreover, investigation of ganglion cell function may provide insights into the underlying pathogenesis of ONH.

Amount requested: \$14,000

Amount raised to date: \$1,300 🍀



Pamela and Cassandra recognized by Debbie for their hard work



## DR. TADANORI TOMITA, MD

Yeager Professor of Pediatric Neurosurgery, Head of Division  
Children's Memorial Hospital, Chicago

### Regarding: Neurosurgery and Shunt Research

The generous gifts made by the One Small Voice Foundation have the potential to make a profound difference in the lives of the children who come to Children's Memorial Hospital with hydrocephalus and related serious disorders of the brain. As an important contributor to the area of hydrocephalus care and research in our institution, your gifts are making possible important research investigations with the hope for better and safer treatments, the development and use of promising new technologies and the accumulation and dissemination of data that informs and improves our current clinical practices.

The importance of your support to the Division of Neurosurgery cannot be overstated. Children today and for years to come will benefit from the ripples generated by these gifts. In gratitude, we are pleased to present you with this report on the programs funded through this considerate philanthropy.

Children's Memorial Hospital's highly regarded Division of Neurosurgery is deeply committed to providing comprehensive care for children with hydrocephalus. Each year, we care for more than 1,500 children on an inpatient basis and record as many as 5,000 outpatient visits related to the ongoing management of hydrocephalus. Tadanori Tomita, MD, Yeager Professor of Pediatric Neurosurgery and head of the Division, is overseeing a number of these important initiatives. We are delighted to share with you some updates on these projects, below.

One of the most exciting projects to emerge in the past year is the planned development of an innovative shunt system that would greatly improve the lives of children with hydrocephalus. Hydrocephalus results from the build up of cerebrospinal fluid (CSF) in the brain. This fluid is normally drained out of the brain and gets absorbed. When there is a disruption in drainage, absorption and production of CSF, there is increased pressure within the brain, causing neurological problems. Children with hydrocephalus require shunts to drain cerebrospinal fluid. This is typically done by surgically placing a ventricular shunt inside the brain.

Quality of life for children with shunts may be affected, due primarily to the high rate of shunt-related infections, malfunctions and other problems that require ongoing surgical revisions. Dr. Tomita reasons that a wireless system could be developed that would involve implanting a tiny computer capable of monitoring the intracranial pressure (ICP) and regulating the shunt valve. The first step in this process is the ICP monitor, which would emit radio signals that can be picked up from the outside. When that is accomplished, the shunt device would open and close, according to the patient's needs. This is Dr. Tomita's plan.

Dr. Tomita has been interviewing possible candidates capable of collaborating on the construction of such a device. Initial discussions with a candidate at Northwestern University did not work out. Since then, he has identified a team of two engineers from the University of Illinois who believe they can produce a manufacturable prototype for ICP monitoring. Discussions are ongoing, and Dr. Tomita expects to review a prototype in the near future.

This intricate project is only in its initial stage, but as we make advances, our hope is in the not-too-distant future we will be conducting studies involving placing this remarkable device in patients' brains and possibly greatly altering our course of future treatment for this serious condition.

For more information please visit our website at [www.onesmallvoicefoundation.org](http://www.onesmallvoicefoundation.org) you will find Dr. Tomita's complete report. 🍷

## DORY KRANZ

Executive Director

Hydrocephalus Association, San Francisco

### Regarding: Research Update 2007

The Hydrocephalus Database Research Project, made possible by generous grants from the One Small Voice Foundation and Medtronic Foundation, continues to provide critical data to researchers. This self-report patient database was started by Hydrocephalus Association past board member, Cynthia Solomon, to capture quality of life outcome data on people living with hydrocephalus. The database comprises over 2,000 data points and is a valuable source of information for clinicians and researchers. It is our pleasure to share a few of the exciting projects currently underway.

Many people who live with hydrocephalus struggle with headaches. Dr. Harold ReKate of Barrow's Neurological Institute in Phoenix, Arizona approached the Association for help quantifying the issue of headaches and hydrocephalus. Preliminary analysis of a question about "frequent chronic headaches" showed them to be quite common in children and young adults with hydrocephalus. This analysis was presented at the Pediatric Section meeting of the American Association of Neurological Surgeons/Congress of Neurological Surgeons meeting in Denver in December, 2006. Dr. ReKate is currently writing a paper on these findings for publication in a peer-reviewed journal.

We are getting our first glimpse of data on the impact of hydrocephalus over many years. Nalin Gupta, MD PhD; Yvonne Wu, MD MPH; Margaret Wrench, PhD; and Jeanna Park at the University of California, San Francisco recently completed a paper on long term outcomes of patients with treated childhood hydrocephalus. This paper has been accepted for publication in the May 2007 issue of *Journal of Neurosurgery: Pediatrics*. Once the paper has been published, we will be able to share some of the findings with you. Stay tuned...

We at the Association are most grateful to the Katzbeck's and the One Small Voice Foundation for making this Database Registry project possible. Through research and better understanding, lives are changing for the better. 🍷

## 2006 AND 2007 ZACH AWARDS ZGraphics, Ltd. and HSM



Joe Zeller accepting the  
2006 Zach award

In June of 2006, we honored Joe and LouAnn Zeller of ZGraphics, Ltd. with the Zach Award. Joe and LouAnn have been supporting the foundation since its inception. They created our logo and stationery; design all of our invites and newsletters and financially support events. Joe and LouAnn have been an integral part of the success of the foundation—we could not have done it without them, Thank you!



Beth Tarnoff accepting the  
2007 Zach award

In March of 2007, we honored HSM Electronic Protection Services, Inc., A Stanley Works Company. HSM Electronic Protection Services has been supporting the foundation for several years. They have been the underwriter for the Open Toe Shoe Party for two years and the support of their staff and their belief in our mission earned them the 2007 Zach Award. Thank you!

Both ZGraphics, Ltd. and HSM Electronic Protection Services truly exemplify the meaning of the Zach Award—in one word GENEROSITY. And not just financial generosity, but spiritual generosity as well. Thank you both for your uplifting spirit and dedication to our foundation. Your support has been a crucial part of our success.

Continued from cover...

## WHAT IS OPTIC NERVE HYPOPLASIA?

(Formally called septo-optic dysplasia or deMorsier's syndrome)

Optic nerve hypoplasia is the under development or absence of the optic nerve combined with possible brain and endocrine abnormalities. ONH is the SINGLE leading cause of blindness and visual impairment in children. In some instances ONH includes agenesis (absence) or abnormal development of the corpus callosum and septum pellucidum. These abnormalities can be minor and not cause abnormal brain functions or the brain function can be affected ranging from mild to severe. The areas that can be affected involve gross and fine motor skills; and include intelligence, speech and interacting with people and in some people these abnormalities cause seizures.



Jeremiah



Kambree

The development of the pituitary gland can also be affected by this disorder. The pituitary gland is found at the base of the brain. It is the body's master control gland; it makes and directs important hormones required for growth, energy control and sexual development. When a person doesn't make hormones correctly this is called hypopituitarism. The lack of these hormones in children can cause a great number of medical and developmental problems.

Children need growth hormone to grow normally, control their metabolism, grow and maintain strong bones. The thyroid hormone contributes to the body's ability to grow normally and helps control the body's metabolism (ability to make energy). The pituitary gland also signals the adrenal glands to produce cortisol. Cortisol is needed in times of physical and emotional stress. The pituitary gland produces ACTH, which signals the adrenal gland to produce cortisol in times of stress (such as surgery, illness, dehydration). In addition, you can have problems with development of sex hormones, low blood sugar and if the body is producing too much ADH causing the body to produce too much urine.

All of these endocrine conditions can be managed through daily medication routines. The medications are delivered by nose, mouth or injection. Even with close and careful monitoring these endocrine deficiencies can be dangerous to those afflicted and possibly deadly. ❤️

(This information was summarized from *Optic Nerve Hypoplasia, A Guide for Parents*, written by Dr. Francine Kaufman, Dr. Neal Kaufman and Dr. Mark Borchert. For a complete guide, please see our website [www.onesmallvoicefoundation.org](http://www.onesmallvoicefoundation.org)).

# Third Annual Open toe Shoe Party!



2007 Open Toe Shoe Party Winner Shari Flaughter with runners-up Linda Watters and Hailey Swinney

On Saturday, March 24, 2007, the One Small Voice Foundation hosted its Third Annual Open Toe Shoe Party in Santa Monica, California. The event was generously underwritten by HSM Electronic Protection Services, Inc., A Stanley Works Company. The event was a smashing success as a result of the generosity of HSM and all of whom were in attendance. It was a beautiful day in Santa Monica and everyone was showing off their best open toe shoe look for Spring 2007. An amazing luncheon was prepared by the Loews Hotel with wonderful wine provided by Stuart Wine Cellars (thank you Marshall and Susan) and everyone cruised an amazing silent auction which included items

such as a John Mayer autographed guitar and a week-long stay in beautiful San Jose Del Cabo. Our celebrity judge panel—Linda Hamilton, Nanny Stella, Kirsten Vangness, Tracey Bregman, Michelle Stafford, Susan Stuart (2005 Winner), Charity Prestifillipo (2006 Winner), Beth Tarnoff (HSM Electronic Protection Services) and host Dave Walsh—carefully scrutinized the well-heeled contestants to determine who sported the best open toe shoe for 2007. When the results were in, we had an event first—a three-way tie for first place! After we turned the decision over to our audience, winner Shari Flaughter was named our first place winner, Linda Watters our second place winner and Hailey Swinney our third place winner. In our eyes all of the contestants were winners! We also had a great time with our first-ever 13 and under category—all of the children who participated were winners.

The event raised a record amount for the foundation.

As result of our generous underwriters HSM Electronic Protection Services, Inc.; Stuart Cellars; our silent auction donors; and specialty boutique vendors—we donated \$29,411.57 to Childrens Hospital Los Angeles for Dr. Mark Borchert's very important research of Optic Nerve Hypoplasia.

Thank you to all who helped make this event possible: Ivey and Eric Steinberg; the event committee; Stephanie Smith-Joseph and the volunteers from Childrens Hospital Los Angeles; and to everyone who attended. We look forward to seeing you next year! ❤️



Celebrity Judges—Nanny Stella, Kirsten Vangness, Linda Hamilton and Charity Prestifillipo

## Upcoming Events

Thank you in advance for attending our events. Please know we offer a variety of events for your enjoyment. We appreciate your support and do not expect that everyone is interested in attending all events.

We are currently looking for volunteers, if you are interested in volunteering to help with an event or would like to be a part of an event committee, please email us at [onesmallvoice@earthlink.net](mailto:onesmallvoice@earthlink.net)

### 6TH ANNUAL 5K FAMILY FUN WALK

Sunday, September 16, 2007

Retired Train Depot, Elmhurst, Illinois

Take a beautiful walk with your family and enjoy face-painting, 101.9fm THE MIX Road Crew and lots of fun! Online registration will be available in August. \$20.00 per individual/\$30.00 per family.

### 8TH ANNUAL WARM UP FOR SUMMER INDOOR GOLF OUTING

Saturday, January 26, 2008

Watch your mailboxes for more details!

### 4TH ANNUAL OPEN TOE SHOE PARTY

Saturday, April 5, 2008

Santa Monica, California, Loews Hotel Santa Monica Beach

Save the date...more information coming soon!

Please watch our website for more details to come regarding events! ❤️



# Thanks to our Corporate Sponsors

In addition to the amazing support of The Orion Group and its business partners ZGraphics, Ltd., Genesis Press, Mallard Press and Vision Mailing Services, we have many generous sponsors and event underwriters who have made our success possible. Thank you to all of our sponsors and underwriters—it is because of your continued support that nearly 100% of your donations go directly to research.

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- ZGraphics, Ltd.

## A SPECIAL THANK YOU...

to Lombard Cub Scouts Pak 40 scouts and parents and Immaculate Conception High School students. They were an amazing part of the success of the 2006 5K Family Fun Walk. Thank you for all of the pledges you raised and for all of your help setting up, providing safety assistance and cleaning up. Thank you also to Macarthur Middle School for selecting our foundation for your fundraising efforts—we look forward to seeing you all in September 2007.

## Attention All Optic Nerve Hypoplasia Families!

Please play a role in groundbreaking research. Go to the One Small Voice Foundation website to connect to the online research survey [www.onesmallvoicefoundation.org](http://www.onesmallvoicefoundation.org). Thank you in advance for taking the time to be part of this very important research.

# Photo Gallery YOU ALL HELPED MAKE 2007 A GREAT SUCCESS!



*Our littlest golfer Erin Vachlin*



*Pak 40 Lombard and Zachary 2006 5K Family Fun Walk*



*Debbie Katzbeck with Al Hogan winner of the Longest Drive Contest at our 7th Annual Golf Outing*



*Team Calico Inn*



*Open Toe Shoe Party check presentation*



*Chris Wozniak, Diana Brown and Jill Pena—Winners at our Warm Up for Summer Event*



*Open Toe Shoe Party past winners Charity and Susan enjoy an afternoon at the Loews Hotel*

# A Debt of Gratitude

BY IVEY STEINBURG



I am humbled daily by my son, Jack Steinberg.

Jack will be 4 years old in August, and was diagnosed with Optic Nerve Hypoplasia before his first birthday. Fortunately, his vision is the least of our concerns, as it is actually quite good. His motor skills are delayed and he has received physical, occupational and speech therapies, as well as swimming and horseback riding lessons, for the majority of his time here on earth.

Anyone who has ever been frustrated by learning a new skill could take a lesson from Jack's seemingly endless perseverance and sunny disposition. He strives for the independence most children his age take for granted—being able to push himself into a seated position, walking independently, speech that can be understood—and yet he never shows envy or resentment toward typical children. He delights in watching his friends run around and is very loving to those who are even more challenged than he.

He is the proud owner of several adaptive devices—a communication system similar to a keyboard, a tricycle, a gait trainer, a wheelchair, a stander and a toileting system. We're fortunate to have good support

from our insurance company and we continue to seek out anything that will enable him to gain more independence.

Jack's cognitive skills are quite good; he is on target with his receptive language and has been known to answer questions before the peer models in his class. His sense of humor is contagious, and we as his parents make regular fools ourselves just to hear his deep-throated giggle.

Prior to Jack's arrival into my waiting arms, I was on a treadmill at the highest setting, a fast-paced career track, with a circle that included the familiar faces of celebrity. I am now surrounded by people who are more than VIPs; they are the embodiment of the good in life. These teachers, therapists, doctors and friends are so invested in helping kids like Jack; they have hearts as big as a Montana sky.

I was given a gift when I became Jack's mom and I'm savoring every delicious moment. I no longer question why I was the chosen lucky one; rather I'm fortunate enough to have found out what I'm to do with the rest of my life. I am blessed to be in his audience. ❤️

## HELP OUR MARATHON TEAM Sunday, October 7, 2008

Zachary's father Kevin Katzbeck, along with Barb, Kathleen, Lauren and Amanda Krzystofiak and Megan Frawley will be running the Chicago Marathon. Please watch our website at [www.onesmallvoicefoundation.org](http://www.onesmallvoicefoundation.org) for more information about how you can help them raise funds for One Small Voice Foundation or where you can go to cheer them on during the marathon. This special team of runners will be devoting the next 5 months to training for Zachary and other children affected by optic nerve hypoplasia and hydrocephalus. Please keep them in your thoughts and prayers and sponsor them for the marathon. If you are currently training for the marathon and would like to know how you can help raise funds for the One Small Voice Foundation, please call Debbie Katzbeck at 630/620.6637.

## UNITED WAY

### Dear Friends of the Foundation,

If you work for a corporation and are encouraged to donate to United Way, please know these donations can be designated to go to the One Small Voice Foundation. Please file the appropriate paperwork when signing up for United Way and these donations can further help the children afflicted with Hydrocephalus and Optic Nerve Hypoplasia.

If you need any additional information in order to expedite this donation, please call Debbie Katzbeck at 630/620-6637.

Thank you,  
One Small Voice Foundation Board of Directors

## KOHL'S CARDS ATTENTION SHOPPERS!

We have joined forces with Kohl's department stores to raise money for the Foundation. If you purchase a Kohl's gift card from the Foundation, 5% of your purchase goes to the Foundation. Please call Cathy Baker at 630/739-5297 if you would like to purchase a gift card or stop by The Spice Merchant and Tea Room at 108 W. Park Blvd, in Elmhurst, IL (phone 630/941-7288). They are great to keep around for last minute presents or for your own shopping. Thank you again for your support.

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One Small Voice Foundation is a nonprofit 501(c)3 organization supported by the generous contributions of individuals, corporations and foundations. We thank you for your support.

MISSION STATEMENT: Inspired by the love and generosity of our supporters, we strive to give a voice to all children with Optic Nerve Hypoplasia and Hydrocephalus. We will educate and inform others about these disorders. We will support research efforts to benefit children with Optic Nerve Hypoplasia and Hydrocephalus. Our mission will be accomplished with the highest level of integrity and commitment.

email: [onesmallvoice@earthlink.net](mailto:onesmallvoice@earthlink.net)  
[www.onesmallvoicefoundation.org](http://www.onesmallvoicefoundation.org)

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