

Dear Friends of the Foundation,



Celebrating Zak's fourth birthday after his return from the hospital

It is hard to believe a year has passed since our last newsletter. This year has been filled with happy, exciting, frightening and difficult moments. The foundation continues on as a result of our loyal board members, volunteers and supporters. Our family has been going through a particularly rough patch due to Zachary's medical conditions. As a result, we are driven to continue the work of the foundation.

This past September, as we were preparing for our 2nd Annual 5K Walk and first Ralph's World concert, Zachary began having seizures again. Prior to this, he had been seizure free for over two years because his medication and shunt were working properly. Since September 3rd, Zachary has had to endure the following: over 12 (15 minute plus) grand mal/tonic-clonic seizures, 10 neurosurgeries to repair his shunt—which malfunctioned nine times for a variety of reasons—and a number of cortisol (stress hormone) crises due to the stress of the seizures and surgeries. Zachary spent most of September, October and November hospitalized; he had a six-week break and then was hospitalized multiple times in December, January and February. We came close to losing him several times because the intra-cranial pressure combined with the absence of his stress hormone caused his heart to slow down to a dangerously low rate. He spent Halloween, Christmas and his birthday at the hospital, in critical condition. In an attempt to make-up for this, we took Zach and Ben to Disney World. On the plane home, Zach had another seizure. We had to make an emergency landing in Atlanta and airlift Zach to a Children's Hospital. Upon returning home we continued to face more medical challenges, more seizures and cortisol crises and another shunt malfunction.

Despite these challenges and extremely frightening situations, we remain determined to move forward with the foundation. Many of you ask "why?" and the answer is simple: We have to help the research teams in every way we can. Which is why we are coming to you again today—we are kicking off our 2004 annual appeal!

Included in this newsletter is an envelope. **Our goal is to collect \$100,000.** Just think if each of our supporters could donate \$100.00, we could meet and exceed our goal—imagine the difference we could all make if we met this goal! We realize that recent economic times have made finances tight for many families, so we are extremely grateful for any support that you are able to share with the foundation. Please consider making this donation.

In our newsletter today, you will receive information on the research your monies are supporting Optic Nerve Hypoplasia research being conducted at Children's Hospital Los Angeles (which includes endocrine related areas) and the neurosurgical research being conducted at Children's Memorial Chicago and through the Hydrocephalus Association. You will also read brief overviews of these two diseases, a pictorial of recent events, a calendar of upcoming events and a photo of our Board of Directors.

As always, thank you for all of your love, prayers and monetary support. The One Small Voice Foundation would not exist if it were not for everyone's support. As a result of your generosity, children's lives are being changed.

God Bless you all,

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

Zach and Ben, happy that Zach's home after a 4-week stay in the hospital!

WHAT IS HYDROCEPHALUS?

Hydrocephalus comes from the Greek "hydro," meaning water, and "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



Zach at the pumpkin farm.

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 incidences 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, this cannot be used for all patients.

This definition was taken from the Hydrocephalus Association website. (www.hydroassoc.org) If you have hydrocephalus or are a parent of someone with

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Updates from the Desk of...

PAMELA GARCIA-FILION

Research assistant to Dr. Mark Borchert,
Children's Hospital Los Angeles

Through the support of the One Small Voice Foundation, the ONH research study at Children's Hospital Los Angeles has proudly taken the shape of a clinical research program for families with children diagnosed with ONH. Our research continues to grow and reach milestones demonstrating progress towards answering the many questions surrounding ONH.

In January, we were pleased to provide the One Small Voice Foundation with a preliminary findings report to post on-line to share with families the frequency and distribution of clinical risk factors and outcomes facing children with ONH. The details and statistics from our preliminary findings will be available through journal publications to follow—so keep an eye out for availability notification. These findings have directed our research attention to develop 'carve out' studies for further research of emerging issues, such as endocrine and developmental outcomes. We have also expanded the epidemiology branch of our study to explore the distribution of this disease in addition to the potential risk factors.

We are proud that, in addition to the research objectives, our study has grown into a resource-based, family-centered research program to provide support, information, easy access for physician specific inquiries and service referrals for therapy and education planning. We regularly receive calls from families, in and out of the research study, that have questions, need information or just simply need to talk. We are pleased to be able to provide this support and guidance in a coordinated and efficient manner. It has proven to be invaluable to our families everywhere and wouldn't be possible without the One Small Voice Foundation.

Our appreciation for the support of the One Small Voice Foundation extends beyond words and can only be adequately expressed by our research and program efforts. The donations from the One Small Voice Foundation strengthen our ability to conduct research and serve as a resource to all families with children diagnosed with ONH—in and out of our study.

EMILY FUDGE

Founder, Hydrocephalus Association

The goal of the Hydrocephalus Database Project is to create a national registry that will enable the Hydrocephalus Association to collect, store and synthesize information on the diagnosis, treatment and incidence of hydrocephalus, as well as its lifelong impact on individuals.

For the past 16 years, representatives of the Hydrocephalus Association have attended and exhibited at the annual meeting of the American Association of Neurological Surgeons/Congress of Neurological Surgeons Section on Pediatric Neurological Surgery. This is a three-day meeting held in various cities around the United States every December and attended by an average of 250-300 pediatric neurosurgeons. It is "the" professional gathering for neurosurgeons who have a focus and specialty in pediatrics. Past

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.** Just file the appropriate paperwork when signing up for United Way, and your donations can further help children afflicted with Hydrocephalus and Optic Nerve Hypoplasia.

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

Thank you,
The One Small Voice Foundation Board of Directors

MEET OUR BOARD OF DIRECTORS



Standing (left to right): Amy Frost, IT team leader with Abbot in Waukegan; Richard Welin, owner of The Spice Merchant and Tea Room in Elmhurst and OSV treasurer; Cathy Baker, retired administration manager of the BP Foundation; Sharon Welin, teacher and owner of The Spice Merchant and Tea Room; Lenore Welsh, a microbiologist at Loyola University Hospital. Sitting (left to right): Melanie Wiseman, director of recruiting at Boise in Itasca; Diana Brown, school psychologist and OSV secretary; Kevin Katzbeck, owner of The Orion Group and OSV vice president; Debbie Katzbeck, mom to Zachary and Benjamin and OSV president. Not pictured: Chris Wozniak, retired from operations and finance at Ameritech.

presidents of the Section include doctors Fred Epstein, Harold Hoffman, David McLone, Michael Scott, Harold Rekate and Marion (Jack) Walker.

Over the course of the three days, approximately 50 papers are presented—customarily about a quarter of these have to do with some aspect of hydrocephalus. Since 1989 the Hydrocephalus Association has presented the Resident's Award to the best paper on hydrocephalus presented at this meeting.

At the 32nd Annual Meeting of the Pediatric Section in Salt Lake City in December 2003, the Association was invited to make a preliminary report on the Hydrocephalus Database Project. This was the first time that a nonprofit organization has been asked to address this prestigious body, which was both an honor for the Association and a recognition of the importance of the Database Project.

THE NEUROSURGERY TEAM

Children's Memorial Chicago

The Division of Neurosurgery provides services for every aspect of surgical disorders affecting the brain and spinal cord in childhood. All in all, it has been a busy and productive year for the program—both in the clinic and the laboratory. Since assuming chairmanship of the division a year ago, Tadanori Tomita, MD has focused much of his time on strengthening the neurosurgery team. In November, Dr. Arthur DiPatri was recruited from the University of Maryland. Dr. DiPatri, who previously trained in Children's Memorial's fellowship program, is skilled in the fields of spine and epilepsy surgery. Neurosurgeon Todd Alden, MD also will join the neurosurgery team in August upon completing his fellowship training at Seattle Children's Hospital. Dr. Alden specializes in epilepsy surgery and will divide his time between surgical and research activities.

Research. While helping families cope with the day-to-day complications posed by illness is a primary concern of the Division of Neurosurgery, we also understand the only way to improve the level of clinical care is through the continued pursuit of new treatments emanating from research. Current clinical and basic investigations are:

- Examining the use of a procedure called third ventriculostomy for the treatment of hydrocephalus. This procedure involves the creation of a channel to reestablish the free flow of fluid within the interior of the brain
- Developing therapies for Chiari malformation, a benign structural problem affecting the cerebellum
- Studying long-term outcomes of youngsters impacted by severe neurotrauma and myelomeningocele (spina bifida)
- Examining the molecular biological mechanism of spina bifida

The division's commitment to research is fostering the discovery, development and delivery of life-altering treatments and therapies. ❤️



Ben scouts out the best pumpkins

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hydrocephalus, please go to the website and register in the research database.

WHAT IS OPTIC NERVE HYPOPLASIA?

Optic nerve hypoplasia, (sometimes called septo-optic dysplasia or deMorsier's syndrome) 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; intelligence, speech and interacting with people and, in some people, these abnormalities cause seizures.

The development of the pituitary gland can also be affected by this disorder. The pituitary gland is found at the base of the brain and 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 can cause a great deal of problems for the children who are missing them.

Children need growth hormones to grow normally, control their metabolism and maintain strong bones. The thyroid hormone contributes to the bodies' ability to grow normally and helps control the bodies' 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 time 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 of these endocrine deficiencies, it can be dangerous to those afflicted...without careful monitoring, these conditions can be 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.)

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.)

4TH ANNUAL GOLF OUTING

June 13, 2004

Maple Meadows Golf Course

272 Addison Road, Wood Dale, Illinois

\$125.00 per golfer; \$25.00 per additional barbeque guest

Texas Style Barbecue immediately following event at the Clubhouse! Great contests and prizes, including a chance to win a Saab convertible from Patrick Dealer Services! Please make checks payable to One Small Voice Foundation, include the names and phone numbers of your foursome* and mail to One Small Voice Foundation, P.O. Box 644, Elmhurst, Illinois, 60126. Make note that price includes golf, cart and dinner. If you are interested in sponsoring a hole or the barbecue, or if you have any questions, please call Debbie at 630/620-6637.

Assigned tee times will be posted on our website one week prior to event. Registration deadline is June 1, 2004. (www.onesmallvoicefoundation.org)

**If you do not have a foursome and would like to golf, we would be happy to place you with one.*

THE MIX 101.9 CHILDREN'S MEMORIAL HOSPITAL RADIOTHON

August 13 and 14, 2004

Listen for Debbie, Kevin, Zachary and Benjamin when they join the Mix's Eric and Kathy to help raise funds for Children's Memorial Hospital.



The Katzbeck's with Eric and Kathy of The Mix, at the 2003 Children's Memorial Hospital Radiothon

SUMMER FUN CRUISE

August 28, 2004

Navy Pier, Chicago, Illinois

Leave from Navy Pier for a lakefront tour complete with music, open bar and appetizer buffet. Plus...Fireworks!

3RD ANNUAL 5K WALK

September 26, 2004

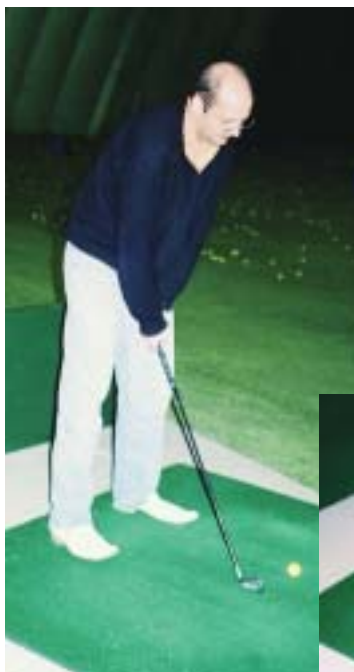
Elmhurst, Illinois

Save the date!!! More details to come soon!

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

Golf Dome

Thank you to all who attended the Warm-Up for Summer event at White Pines Golf Dome. A special thank you to Mike Munro who graciously donates the facility each year. We'd like to share a few pictures from the evening.



Stuart Thompson carefully lines up his shot



Gold Dome raffle winners Ken Nagle, Ken Nagle Jr., Matt Hejna and Ann Jenkins



Kieran Thompson has fortunately inherited his mom Ellen's swing

Greeting Cards

ATTENTION: ALL "LITTLE PICASSOS"

We invite all children to submit artwork that represents any of the following: Christmas, Birthdays, Get Well Soon, Anniversaries or a favorite picture for any occasion. Your child can submit one design or several designs that, if chosen, will be part of a 12-card set available for purchase later in the year. Check our website for the finalists and availability. Please submit color artwork, each no larger than 8.5 x 11, by September 1, 2004 with child's name and age. As a result of the generosity of TARCO printing, 100% of the proceeds from the sale of these cards will go to research. (Artwork will not be returned, and will become the property of the One Small Voice Foundation.)

Calico Inn

Thank you again to all of the guests of the Calico Inn. The guests of the Calico Inn have been great supporters of the One Small Voice Foundation. The 2003 winners of a free night stay at the Calico Inn are Rosemary and Duane Lewis. Thank you Rosemary and Duane and all the guests who donated this year—we really appreciate all of your support and prayers. In addition to the Lewis' donation to the foundation, Rosemary made a special quilt for Zachary. Zachary and Ben love cuddling together with this blanket as they watch their favorite movies. Thank you again, Calico Inn!!



Duane and Rosemary Lewis won a night at the Calico Inn!

Shop Kohl's to Help OSV

We have joined forces with Kohl's department stores to raise money for the foundation. If you shop at Kohl's, we are selling gift cards. You can purchase a Kohl's gift card directly from the foundation and 5% of your gift card purchase goes to the foundation. Please call Cathy Baker at 630-739-5297 if you would like to purchase gift cards. They are great to keep around for last minute presents or for your own shopping. Thank you again for your support.



ZAK AND LIZZIE

Author Ann Malokas and Lenore Welsh (Lizzie's Mom, Zachary's adopted Aunt, trusted friend and board member) continue their tireless efforts to promote the *Zak and Lizzie* story and our foundation. Last year was a presidential year as *Zak and Lizzie* made it to the White House and former First Lady Barbara Bush's Texas library. This year our beloved Ann and Lenore have traveled coast-to-coast presenting our story. We THANK YOU from the bottom of our hearts!!

If you haven't already made a donation to receive a copy of *Zak and Lizzie*, it's not too late, but copies are LIMITED. *Zak and Lizzie* is the heartwarming and true story of our son Zachary and a friends "rag-mop dog" named Lizzie. You can receive

a copy by making a donation to One Small Voice Foundation, P.O. Box 644, Elmhurst, Illinois 60126, the cost is \$15, which includes shipping and handling.

In addition to continuing to promote *Zak and Lizzie*, author Ann Malokas has created a second masterpiece. Keep your eyes open for *Zak, Lizzie and Ben, A Tag-a-long Trio*. The second story tells how Zak and Lizzie welcome Ben and how with the help of Zak and Lizzie, Ben is able to understand all of the special challenges that come with a special brother.



Lenore Welsh and Ann Malokas, OSV's Dandy Duo

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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, while supporting research efforts that benefit children with optic nerve hypoplasia and hydrocephalus.

email: onesmallvoice@earthlink.net
www. onesmallvoicefoundation.org

P.O. Box 644
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