

Greeting Cards

ATTENTION: ALL "LITTLE PICASSOS"

Your child can submit one design or several that, if chosen, will be part of a 12-card set available for purchase later in the year. 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. Check our website for the finalists and availability. Please submit color artwork no larger than 8-1/2 x 11 by February 1, 2005 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.)

UNITED WAY

Dear Friends of the Foundation,

If you work for a corporation and are encouraged to donate to the 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 HOLIDAY SHOPPERS!

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. If you purchase the gift card from the Foundation, 5% of your purchase goes back to the Foundation. Please call Cathy Baker at 630/739-5297 or stop by The Spice Merchant and Tea Room at 108 W. Park Blvd, Elmhurst, phone 630/941-7288 if you would like to purchase a gift card. They are great to keep around for last minute presents or for your own shopping. Thank you again for your support.

THE MIX 101.9 AND ONE SMALL VOICE FOUNDATION

A special THANK YOU to 101.9fm The Mix in Chicago! In addition to hosting the annual radiothon, The Mix has selected the One Small Voice Foundation as the beneficiary of this year's MIXclusives box set.

This holiday season, make sure you pick up a copy of the new MIXclusives Box set from 101.9fm The Mix. It's a collection of unique performances from MIX artists including John Mayer, Dave Matthews Band, Bon Jovi, The Goo Goo Dolls, Matchbox Twenty and more!

This four CD set can only be purchased in THE MIX store at wtmpx.com, you can link to this site by going to www.onesmallvoicefoundation.org. While you are there you can listen to a clip from this year's radiothon.



Kathy and Eric with the Katzbecks at the annual radiothon.

Design by ZGraphics. Printing by Tarco. Mailing by Vision Mailing Services. Postage from The Orion Group.

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

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

P.O. Box 644
Elmhurst, IL 60126

F O U N D A T I O N
One Small Voice

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Dear Friends of the Foundation,

It is hard to believe that the holidays are fast approaching and that another year is coming to an end. We want to take a moment to wish you all a happy and safe holiday.



Zachary and Benjamin Halloween '04.

It has been an amazing year for the foundation and our family with the foundation reaching a major milestone. Since our inception, we have donated over \$100,000 to the research we are supporting (please see breakdown below). Our annual appeal is off to a good start and we hope to close the year with a flood of holiday donations. If you have already donated to the 2004 Annual Appeal, THANK YOU! If you haven't, please consider choosing the One Small Voice Foundation for a holiday donation and help us reach the \$200,000 donation mark in 2005.

As most of you know, 2003 was a very difficult year for our family. Zachary experienced major complications with his shunt and seizure activity, and these complications continued into the first part of 2004 with more shunt malfunctions, seizures and cortisol crises. We are happy to report that Zachary—although still battling the absence of cortisol (stress hormone)—he is having fewer breakthrough seizures and his shunt is working correctly (thank you God!).

This newsletter contains information about the diseases we are battling, and updates from the Hydrocephalus Association on their research database and from Pamela Garcia-Filion on the optic nerve hypoplasia research being conducted at Children's Hospital Los Angeles. In addition, we have some important information about new ways to donate and fun updates about recent fundraisers.

We hope you enjoy this newsletter as much as we enjoy putting it together for you. We wish you all a safe and blessed holiday...and we thank you all for your love, support, prayers and monetary donations that have made the One Small Voice Foundation a success.

God Bless you all,

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

OPTIC NERVE HYPOPLASIA

Attention All Optic Nerve Hypoplasia Families!

Be a part of groundbreaking research. Please go to the One Small Voice Foundation website to connect to the research survey. This survey can be completed online, and information gathered will be used for a better understanding of ONH. We appreciate you taking the time to be a part of this very important research.

DISBURSEMENT REPORT

As the foundation closed its fourth fiscal year (August 2004), we are pleased to announce that we have broken the \$100,000 mark in donations received and disbursed.

As a result of your generous donations and the generosity of our corporate sponsors (The Orion Group, ZGraphics, Tarco Printing and Vision Mailing), we have donated \$113,100 to Children's Hospital Los Angeles, Children's Memorial Chicago, the Hydrocephalus Association and The Guild for the Blind. The donations were distributed as follows:

- Children's Hospital Los Angeles: \$82,300
- Children's Memorial Chicago: \$19,300
- Hydrocephalus Association: \$8,000
- The Guild for the Blind: \$3,500

Thank you all for your continued support. If it were not for your generosity, we would not have met this incredible milestone.

WHAT IS HYDROCEPHALUS?

Hydrocephalus comes from the Greek: "hydro" means water, "cephalus" means 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 incidences of adult-onset hydrocephalus and acquired hydrocephalus are not known.



Zachary with Dr. Borcher

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 a parent please go to the website and register in the research database.

Continued on inside...

Updates from the Desk of...

PAMELA GARCIA-FILION, MPH

Clinical Research Coordinator, Division of Ophthalmology
Children's Hospital Los Angeles

Regarding Optic Nerve Hypoplasia research:

As the end of 2004 approaches, we are pleased with the progress of the optic nerve hypoplasia (ONH) research study. Over the past year, we have prepared for the implementation of two new studies that will individually investigate detailed clinical and epidemiological aspects of this disease.

Endocrine dysfunction is a common outcome in children with optic nerve hypoplasia, but affects this population in many different ways. To investigate this outcome further, we have created a study that will examine hormone imbalances and growth outcomes relative to treated and untreated growth hormone deficiency. Currently, it is going through the final steps of approval with the Institutional Review Board at Children's Hospital Los Angeles (CHLA) and is anticipated to begin in December 2004.

The most exciting development at CHLA is the design of the first epidemiological survey of optic nerve hypoplasia. This study will be available online by the end of the year and accessible to all families across the nation that have children diagnosed with ONH. This survey research was designed to enable families to participate even if they are not enrolled in the study at CHLA. Families often contact our offices with inquiries about available studies that do not require travel. Well....here it is! The survey will be relatively short and require very little time to complete. Information gathered from this survey will be used to evaluate the distribution of ONH cases in the United States and when they were born. We believe that this is a big step for understanding the etiology of this disease and will pave the road for future epidemiologic studies in to ONH. 

EMILY S. FUDGE

Executive Director
Hydrocephalus Association

Regarding the Hydrocephalus Research Database:

The Hydrocephalus Association is pleased to announce that the first professional statistical analysis of the Hydrocephalus Database is currently in progress. This analysis is under the leadership of Nalin Gupta, MD, Assistant Professor of Neurological Surgery and Director of the Pediatric Neurological Surgery Program, and Yvonne Wu, MD, Clinical Research Director of Child Neurology, both of the University of California, San Francisco Medical Center and UCSF Children's Hospital. Drs. Gupta and Wu, and associates, are preparing to present their findings at the 33rd Annual Meeting of the Section on Pediatric Neurological Surgery of the American Association of Neurological Surgeons and the Congress of Neurological Surgeons in San Francisco in December 2004.

They are analyzing data on over 1700 patients entered into the database and preparing this initial epidemiological study for publication after the December meeting. Depending on their findings, the Database Project—which will be at the halfway mark of its four-year duration in February 2005—may be temporarily closed down for revision and re-design in order to more effectively and efficiently collect meaningful data during the 2nd half of the project.

The Hydrocephalus Database Project has been funded by One Small Voice Foundation, The Medtronic Foundation and The Integra Foundation. We are deeply appreciative of their financial support for this very exciting project.

We look forward to sharing the results of the initial analysis with all of you in the near future, and we encourage those of you who have not yet participated in the study to log onto our website, www.hydroassoc.org, and follow the instructions for completing the survey. This is your chance to share your experiences and make your voice heard. 

On Thursday, November 18, 2004 at Gallery 37 in Chicago, 11 visually impaired and blind students, along with their companions from Farnsworth School in Jefferson Park, painted what love means to them. This incredible project was inspired by the creative juices of Kimberly Grear and Marisa Brown. Kimberly's dream project came to life with the help of Michelle and Kristin, two wonderful art therapists. The project was inspiring to witness and made possible by several generous donors. The project to date has helped raise \$1,000 towards Optic Nerve Hypoplasia research being conducted at Children's Hospital Los Angeles. In addition, this project is also part of a documentary being created by Karen Carter. We look forward to sharing this film with the world.

The project will continue as we prepare to send the student's art on a "Love Tour" to area children's hospitals, concluding with a final gallery event in February 2005. This event will also feature a silent auction of artwork completed by Chicago Area artists. Please enjoy the pictures from the event and watch our website for future details and more information on where you can view the artists' work. 



Kimberly Grear
with students Michelle
and Rachael.



Art therapist working with student.



A sampling of the
Final Masterpieces.



Students create a window to the world.

Continued from cover...

WHAT IS OPTIC NERVE HYPOPLASIA?

(sometimes 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; 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. 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 can cause a great deal of problems for the children who are missing them.



Zachary and Benjamin Halloween '04.

Children need growth hormone to grow normally, control their metabolism, grow 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 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

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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.

5TH ANNUAL WARM UP FOR SUMMER

Saturday, January 15, 2005
White Pines Golf Dome, 7-10pm
500 West Jefferson (Third) in Bensenville

Donation: \$35 per person

Hit unlimited golf balls; enjoy fun contests and great prizes along with an opportunity to register for a clinic with a top Illinois golf pro.

3RD ANNUAL OPEN TOE SHOE PARTY GOES L.A.

Saturday, April 2, 2005
Century Plaza Westin
12Noon-3pm

A secret judge will select the 10 best looks for the celebrity judge panel. The celebrity judge panel will then select the top 3 contestants. The first place winner will receive a trip to Las Vegas for a weekend of pampering at William Whatley of Ambush Makeover's Spa. If you are interested in joining us in Los Angeles, please let us know as we will have a special block of rooms at a special rate.

5TH ANNUAL GOLF OUTING

Sunday, June 5, 2005
Maple Meadows Golf Course
272 Addison Road in Wood Dale
\$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. If you are interested in sponsoring a hole or the barbecue or 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 Friday, May 27, 2005. (www.onesmallvoicefoundation.org)

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

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

Fun at our golf outing...



Kevin and Shawn Katzbeck along with Joe Zeller and Jerry Pish.



The Tucibat and Vachlin families tear up the course.



Zachery Katzbeck and Kyle McMahon share a moment.



One Small Voice Foundation board members and volunteers prepare to start the walk.

...and 5K walk