Established in 2000, the Preeclampsia Foundation already made history as the nation’s only patient advocacy organization for preeclampsia. We expanded that role in 2008 by merging with the HELLP Syndrome Society to better serve the many families impacted by related hypertensive disorders of pregnancy. Along with our dedicated voluntary Board of Directors, Medical Advisory Board, and hundreds of other volunteers across the country, it’s our mission to reduce maternal and infant illness and death by:

• Raising public awareness
• Providing patient support and education
• Improving health care practices, and
• Catalyzing research

Certainly 2013 was one for the books. The year started with a look back at this life-threatening disorder through the popular PBS television show called *Downton Abbey*. In this British historical drama, one of the show’s beloved characters died from eclampsia after giving birth. Although the fictional series represents life in the early 1900s, women in the United States and elsewhere still die or suffer devastating outcomes from the hypertensive disorders of pregnancy.

We seized the *Downton Abbey* opportunity to clarify historical facts and inform viewers through media articles and social media posts that underscored the fact that maternal death is still a tragic and needless complication of pregnancy. We also provided online support to thousands of survivors and families who visited our website after the show aired, many of whom were left grieving because of their own all-too-similar tragedies.

Also in 2013, we added to the Foundation’s historical timeline with our national health observance designation by the U.S. Department of Health and Human Services – May 2013 will be remembered as the first “official” National Preeclampsia Awareness Month. Key to our awareness-building activities in 2013, more than 40 Promise Walk for Preeclampsia™ events showcased support and education during the month.

The rest is history – or it will be anyway. Read on for other ways we made history in 2013 – all of which made possible through the support of hundreds of dedicated friends and benefactors. Please note at the end of this report our listing of Tribute Gift donors who gave so that others may never know the devastating consequences of preeclampsia.

Thank you for your dedication yesterday, today, and tomorrow – until preeclampsia no longer threatens the lives of mothers and babies.

Sincerely,

Eleni Tsigas, Executive Director
FIRST NATIONAL PREECLAMPSIA AWARENESS MONTH MAKES IT OFFICIAL

With our ongoing focus on increasing awareness of preeclampsia and related hypertensive disorders of pregnancy, we celebrated our first “official” National Preeclampsia Awareness Month in May 2013. The Preeclampsia Foundation secured this national designation with support from congressional leaders, the American Congress of Obstetricians and Gynecologists, and thousands of survivors and volunteers. An online “Hear Us Now” petition campaign generated more than 3,000 signatures, and Congresswomen Lois Capps (D-CA), Lucille Roybal-Allard (D-CA), and Gwen Moore (D-WI) each wrote letters to U.S. Assistant Secretary for Health Howard Koh requesting the national designation. On state and local levels, more than 30 government proclamations were secured across the country to raise awareness about preeclampsia and related hypertensive disorders.

A key message throughout all our activities during Preeclampsia Awareness Month is that every pregnant woman should receive detailed information about preeclampsia and its signs and symptoms.
The Promise Walk for Preeclampsia™ Events Set Record

As our signature public awareness and fundraising effort, The Promise Walk for Preeclampsia events were held at 43 locations across the U.S. and raised an all-time national high of $494,000 toward our mission in 2013. More than 5,000 participants had the option to join friends and families at local events or to participate in a virtual event. Special thanks to our local Mission Families who spearheaded efforts to secure media coverage and raise significant donations in their communities, setting new fundraising and awareness records.
RECIPIENT OF HOPE AWARD FOR VOLUNTEER OF THE YEAR

The Preeclampsia Foundation’s annual Hope Award for Volunteer of the Year was given to Johanna Aiken in 2013. This prestigious award was presented to Aiken at the annual benefit dinner, Saving Grace - A Night of Hope, last October in Iowa City. The award recognizes an individual who epitomizes the true spirit of volunteerism and has made significant contributions to the Foundation.

A HELLP survivor, Aiken has been an instrumental member of our volunteer leadership and helped produce a HELLP DVD for those impacted by this severe form of preeclampsia. She also helped establish the presence of our signature public awareness event, The Promise Walk for Preeclampsia. For three years, Aiken dedicated herself as the Central Regional Coach and helped build numerous provider and patient education alliances in her local Chicago community. Aiken remains a tireless advocate not only for those affected by preeclampsia and related disorders, but for those who aren’t here to speak for themselves.

Volunteer of the Year
Johanna Aiken was diagnosed with HELLP Syndrome at 39 weeks and has since dedicated herself to increasing awareness of the disorder. While Aiken had heard of preeclampsia and associated it with high blood pressure, she had never heard of HELLP Syndrome. Thankfully, it was diagnosed early and managed successfully, and Aiken and her daughter both made full recoveries.
HISTORICAL DRAMA SPARKS WIDESPREAD INTEREST

In early 2013, an unexpected plot twist in *Downton Abbey*, a popular British television drama with a robust and loyal American following, brought preeclampsia to the attention of viewers and media across our nation and beyond. When one of the show’s beloved characters died from eclampsia after giving birth, we took the opportunity to clarify historical facts and inform viewers that the maternal death portrayed remains today a tragic and needless complication of pregnancy. Although the fictional drama represents life in the early 1900s, this episode left many viewers grieving also because of their own all-too-similar tragedies. The week after the show aired, visits to our website tripled and we initiated stories in numerous national media outlets, including *CNN, The Daily Beast,* and *National Public Radio.*

Learn more about how *Downton Abbey* helped us shine a light on preeclampsia and its devastating consequences by visiting Preeclampsia.org or click here.
In our unrelenting effort to make preeclampsia a thing of the past, we focused on empowering and educating pregnant women, survivors, families, and others potentially impacted by this life-threatening disorder. With 1.65 million visitors in 2013, our preeclampsia.org website continued to serve as a primary source of education and information. More than 2,000 other websites referred to our website, and the number of our mobile phone visitors nearly doubled in 2013.

Also in 2013, we were named a Global Giving partner by BabyCenter®, one of many partnerships we formed to make motherhood safer for all women. As the #1 pregnancy and parenting digital resource, BabyCenter helped us spread the word, especially about our highly successful Promise Walk for Preeclampsia events. Other dynamic partnerships in 2013 included the American College of Obstetricians and Gynecologists, American College of Nurse-Midwives, Every Mother Counts, Lamaze International, March of Dimes, and Pregnancy Magazine — to name a few.
A shining example of empowerment, Laura Ryan Moakley (left) took full advantage of everything the Foundation has to offer—education, information, research, and support. She continues to participate in our online Community Forum and The Preeclampsia Registry, and organized a team for the 2013 Brooklyn, NY Promise Walk. To give back even more, she donated the proceeds of her photography business to the foundation in 2013—all so that one day, other women and families are no longer threatened by preeclampsia and related hypertensive disorders of pregnancy.

WITH EDUCATION COMES SUPPORT For survivors like Laura Ryan Moakley, the emotional support offered through the Preeclampsia Foundation was also an important part of her recovery. Moakley experienced HELLP Syndrome with her first pregnancy, and her daughter Rowan was born at 32 weeks via an emergency C-section.

“After going through preeclampsia and HELLP, then delivering so early, I was suffering from post traumatic stress,” said Moakley. “I didn’t know where to turn for help, but then I found the Preeclampsia Foundation online Community Forum. I didn’t feel alone or abnormal any more as I read many other survivors’ personal stories. The Preeclampsia Foundation’s website is a wealth of knowledge and support that continues to help me, and I will always be grateful to the many supporters of the Foundation.”

Moakley’s desire to learn the potential impact on her long-term health and have a second child moved her to participate in preeclampsia research conducted by the University of Vermont, an institution that received our Vision Grant funding in 2008. Having recovered from HELLP Syndrome, and with the encouragement of the study’s team members, Moakley sought the advice of a high-risk Maternal Fetal Medicine specialist before becoming pregnant again. In June 2013, she conceived and thankfully didn’t experience severe complications with this second pregnancy, which she attributes to her great team of doctors. Today three-year-old Rowan is thriving and relishes being big sister to her four-month-old brother Rory.
In 2013, the Preeclampsia Foundation released the Illustrated Preeclampsia Symptoms Tear Pad, a patient education tool developed in collaboration with health services researchers at Northwestern University Feinberg School of Medicine in Chicago. The tool effectively informs pregnant women, even those with potentially poor literacy, about preeclampsia. Because preeclampsia is a disorder that can have grave consequences for a mother and her unborn baby, the tool offers information in a way that allows women to understand and remember it, leading them to promptly seek medical attention if they have symptoms related to preeclampsia.

Recognizing the importance of patient education in efforts to reduce maternal mortality and morbidity, the California Maternal Quality Care Collaborative reviewed and adopted the tear pad into its Preeclampsia Toolkit, which has since been distributed and is now being used by hundreds of hospitals in California and dozens of others across the country. The primary aim of the Toolkit is to guide and support obstetrical providers and healthcare organizations to develop processes for timely recognition and an organized response to preeclampsia. A highlight is the identification of “triggers,” or clinical warning signs, that require immediate evaluation by the provider, whether in the prenatal clinic, the emergency room, labor & delivery, or postpartum.

Also in 2013, patient education efforts included the distribution of the information listed to the right. We also partnered with Abbott Vascular to print 15,000 Preeclampsia & Heart Disease brochures and together we distributed nearly 6,000 of them during the year. Altogether, we provided nearly 20,000 education tools to clinicians and hospitals for their patients throughout 2013:

- Preeclampsia Brochure (English) 5,937
- Preeclampsia Brochure (Spanish) 1,502
- Preeclampsia DVD 9
- Preeclampsia & Heart Disease Brochure 5,874
- HELLP Syndrome Brochure 2,537
- HELLP Syndrome DVD 11
- Signs & Symptoms Magnet (English) 550
- Signs & Symptoms Magnet (Spanish) 100
- Symptoms Pads (English) (25/pad) 311
- Rx Pads (Spanish) (25/pad) 114
- Illustrated Symptoms Tear Pad (50/pad) 801

Total 17,746

NEW ILLUSTRATED EDUCATION TOOL INTRODUCED

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NEW GUIDELINES IMPROVE PREECLAMPSIA DIAGNOSIS AND CARE

As one of a 16-member Task Force on Hypertension in Pregnancy, we played a key role in developing new guidelines released in 2013 by the American College of Obstetricians and Gynecologists (ACOG). For the first time, the Task Force Report concluded that preeclampsia can be diagnosed without high levels of protein in the urine (proteinuria). That’s significant because not all patients with preeclampsia have high protein levels, so previously their diagnosis and treatment may have been delayed.

Preeclampsia is now diagnosed by persistent high blood pressure that develops during pregnancy or postpartum with either:

- High level of protein in the urine or one or more of the following
  - Low blood platelet count
  - Kidney or liver problems
  - Fluid in the lungs
  - Brain-related symptoms such as unrelenting headaches and/or visual disturbances

According to the report, one of the biggest changes in preeclampsia management relates to the timing of delivery in women with preeclampsia without severe features, which — according to evidence-based medicine — is 37 weeks. Additionally, the report recommends daily low-dose aspirin to help prevent preeclampsia in very high-risk women, and the use of magnesium sulfate for severe preeclampsia, eclampsia, or HELLP Syndrome. It also reflects an increasing awareness of preeclampsia in the postpartum period and recommends that prenatal education include preeclampsia information.
MATERNAL SAFETY BLUEPRINT OUTLINED

We also played an important role in the “National Maternal Health Initiative: Strategies to Improve Maternal Health and Safety” consensus meeting held in 2013. Motivated by increasing maternal mortality rates in the U.S. in recent decades, the consensus group represented 30 national medical organizations, including the Preeclampsia Foundation.

The consensus group determined that every U.S. birthing facility should have specific practices and equipment to optimize maternal safety in pregnancy. These include so-called “safety bundles,” or safety initiatives, of protocols and equipment to prevent and manage severe hypertension, as well as protocols for supporting patients, families, and staff. Specific early-warning criteria should trigger a maternal evaluation, and facilities should regularly review severe maternal morbidity from a system perspective.

Since this national consensus-building took place last year, we continue to participate on several of the group’s subcommittees to develop the tools and address the protocols recommended through the effort, and are working with New York and other states to extend the impact and reach of our recommendations.

The Preeclampsia Foundation was one of 30 medical organizations that built maternal safety consensus as part of this national health initiative.
Another important milestone marked 2013 with the launch of The Preeclampsia Registry™, a patient and family database designed to aid and accelerate preeclampsia research. The first of its kind, The Preeclampsia Registry focuses solely on hypertensive disorders of pregnancy and brings together survivors, family members, and researchers from all over the world to develop a comprehensive picture of preeclampsia and discover preventions and treatments, including ones that will reduce its long-term impact. By the end of 2013, only four months after its launch, more than 500 individuals had enrolled in the registry.

As a place to share health and pregnancy history, The Preeclampsia Registry provides a significant resource for researchers to gather data and start new studies. Participants of The Preeclampsia Registry can upload their medical records, which makes the information collected even more valuable for scientific research by adding clinical data to patient-provided information. Participants can also view how their responses compare to the entire registry’s population. As always, this information is never shared with qualified investigators without de-identifying it first. All personal information is fully protected as explained in The Preeclampsia Registry’s informed consent process.
VISION GRANT RECIPIENTS STUDY UNDERLYING MECHANISMS OF PREECLAMPSIA

The Preeclampsia Foundation awarded $25,000 research grants to two preeclampsia research studies in 2013. Our Vision Grant recipients were Ana Sofia Teixeira de Cerdeira, MD, Harvard Medical School, and Mandy Bell, PhD, RN, University of Pittsburgh School of Nursing. Our annual Vision Grants are awarded to the strongest scientific proposals recommended by the Foundation’s scientific review committee and a consumer advisory board, and approved by the Foundation’s Board of Directors.

A Research Fellow at Beth Israel Deaconess Medical Center/Harvard Medical School, Ana Sofia Teixeira de Cerdeira, MD, obtained her MD degree and started her residency in Obstetrics and Gynecology in Portugal. After receiving a Fellowship from the Gulbenkian Programme for Advanced Medical Education, Dr. Cerdeira moved to the U.S. to pursue a PhD in the field of preeclampsia. Dr. Cerdeira is working on the immune mechanisms of placentation regulation in health and preeclampsia. Recent evidence suggests that Natural Killer (NK) cells from the immune system at the maternal-fetal interface (dNK) are important for remodeling placental maternal spiral arteries. This process is compromised in preeclampsia and believed to be the origin of the disease. These placental NK cells are different from the ones in blood. Understanding the mechanisms of dNK cell differentiation may have potential applications in developing novel therapeutic approaches for preeclampsia.

Mandy Bell, PhD, RN, is currently a post-doctoral scholar at Magee-Women’s Research Institute in the University of Pittsburgh School of Nursing, where she obtained her Nursing and PhD degrees. Dr. Bell’s study is designed to clarify the role that soluble endoglin (sENG) plays in preeclampsia by investigating if differences in the genetic code of the endoglin gene and related genes account for increased sENG in women with preeclampsia. sENG is a protein that is increased in the blood of most women with preeclampsia. It is not yet known why this protein increases or how it contributes to the disease, even weeks before women become sick. Because vitamin D and oxygen may affect ENG levels, the study also explores the effects of different vitamin D doses and oxygen levels on sENG in cell cultures.
RESEARCH PUBLISHED IN PEER-REVIEWED JOURNAL

In the works for several years, the Preeclampsia Foundation partnered with investigators to publish collaborative research in 2013. The paper, “Prenatal education is an opportunity for improved outcomes in hypertensive disorders of pregnancy: results from an Internet-based survey,” was published in the November issue of *The Journal of Maternal-Fetal & Neonatal Medicine*. Its authors are the Foundation’s Executive Director, Eleni Z. Tsigas, and three preeclampsia researchers: Dr. Anne B. Wallis, Dr. Audrey F. Saftlas, and Dr. Baha M. Sibai.

Their paper reports on our 2008 survey of 754 women in which we found that most received prenatal checkups and regular screenings, but only 42% “definitely” recalled specific education about preeclampsia and only half of those “fully understood” the explanation. However, 75% who understood acted on this knowledge by promptly reporting symptoms and complying with treatment. Of those who did not remember some or any of the education, only 6% took any action.

The difference between these two groups is highly significant. The authors concluded that knowledge enables women to recognize signs and symptoms, leading to earlier diagnosis and management, and to reduced morbidity and mortality. They proposed the adoption of formal preeclampsia education guidelines, a recommendation we have actively pursued with state, national, and international guideline development groups.

SUPPORTING THE WORLD HEALTH ORGANIZATION AND OTHER TASK FORCES

Other research activities included our participation on two World Health Organization (WHO) task forces to identify maternal research priorities for 2015 – 2025, and with Merck for Mothers to prioritize development and implementation priorities in preeclampsia for the next three to five years. We also supported coalitions to increase funding for the *Eunice Kennedy Shriver* National Institute of Child Health and Development (NICHD) and Centers for Disease Control and Prevention (CDC) research associated with prenatal care, e.g. PREEMIE Reauthorization Act. This act is intended to reduce preterm labor and delivery and the risk of pregnancy-related deaths and complications, and to reduce infant mortality caused by prematurity.
OUR FINANCES

Transparency, financial accountability, and stewardship of our resources guide us. In 2013, 83 cents of every dollar went directly to advancing research and education to save lives. Our 2013 audit (available upon request) passed the scrutiny of the independent auditing firm Whittaker Cooper Financial Group. Total 2013 end of the year net assets were $632,614.

INCOME 2013 ($79,999)

- Individuals: $322,087
- Corporations: $167,713
- Special Events: $103,516
- Foundation Grants: $99,980
- Merchandise Sales & Interest: $4,413
- Other: $22,410

EXPENSES 2013 ($849,811)

- Awareness: $371,641
- Management & General: $43,245
- Research: $83,216
- Patient & Provider Education: $77,667
- Advocacy: $46,687
- Fundraising: $53,695

PLEDGE TO ACCOUNTABILITY AND STEWARDSHIP

The Preeclampsia Foundation is committed to transparency, the highest standards of financial accountability, and appropriate stewardship of our resources. We are a 501(c)(3) not-for-profit organization established in 2000. Our Tax ID Number is 91-2073087. Funds received by the Preeclampsia Foundation are carefully monitored to ensure their use complies with donor intent. An annual audit of our finances is conducted by an independent certified public accounting firm and overseen the Preeclampsia Foundation Board of Directors. Board and organization assessments are conducted by an outside party with expertise in board governance and evaluation every two years.

TRIBUTE GIFTS HELP US REMEMBER

A tribute gift to the Preeclampsia Foundation is a special way to honor or remember someone whose life has been touched by preeclampsia, eclampsia, or HELLP Syndrome. Whether honoring a loved one, friend, or colleague, or celebrating a significant event or achievement, tribute gifts serve as a special expression.

When a tribute gift is made, the donor receives a thank you letter and receipt for tax purposes, and the honoree or the family of an honoree being memorialized receives a special notification by mail (gift amounts are not disclosed).

Please consider the Preeclampsia Foundation when you plan a tribute gift in honor or memory of a loved one. Your gifts ensure the future of our mission – raising public awareness, providing education and support, improving health care practices, and catalyzing research.

We thank the donors listed here for their generous Tribute Gifts received in 2013. While every attempt has been made to accurately list those being remembered and honored, please contact us with any corrections.

Donations may be made at preeclampsia.org/donate.
You may contact the Foundation at:
Preeclampsia Foundation
6905 North Wickham Road
Suite 302
Melbourne, FL 32940
Toll-free: 1.800.665.9341
Phone: 321.421.6957
Fax: 321.821.0450
Website: preeclampsia.org
Tax ID Number: 91-2073087
Gifts Received in Honor Of... Continued

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Kelsey Young
Nicole Purnell
Cathy McDaniel
Nellie Hie
Erin Burkhar
Oliver and Sharon Bull
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Brandi Huckaby
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Linda Cowan
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Freda Gordon
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Stacy Kegg
Sella Wall
Steiner Family
Dana Kaplan
Stephanie and Marissa Steiner
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Gina Levy
Sarah Liebhaman
Sheley Hartnett
Julie Steiner
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Susan Brodesser
Emily Pollock
Susie and Marty Fine
Samantha Sauerade
Surrin “Butter” and
Gabriel Sheer
Juliette Chamberlain
Nanay Asay
Sarah Alm
Reneso Pulse
Kim and Todd Truax
Sam Visalli
Sydney and Hudson Rothert
Laura Rothert
Tara Carter
Dorothy Johnson
Tara and Leo Laverty
Brian Laverty
Tayen Parke
Morgan Lundy
Joy Mahoney
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Jaimee Southern
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Tia and Aiah Doster
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Shannon McCarthy
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Addison Marie Cull
Paul Cull
Audrey Flax
Autumn Rayne Ostendorf
Karen Claustru
Taya Turner
Ava and Noah Bunge
Shawn Bunge
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Bailey Rae Griffin
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Nia Lua
Kim Hoa Ung
Michiko Uyeno
Alfredo Vito
Bob Hammond
Kevin Russell
Brandon Proden
Alessandra Drossi
Sara Brunoige
Fay Chin
Lisa Degennaro
Jaquline Graniazi
Gladys Henerros
Michelle Miller
Lisa Pulio
Allison Paulus
Kimberly Paulus
Alyce Nosh
Donna Jennings
Mallory Hope Larsen
Coleen Blickegret
Anka Kacanowski
Anderson MazzeUi Graham
Sharon Kohout
Alma Millicent Bepliske
Laura Johnson
Carrie Jensen
Travis Sullivan
Amanda Boelter
Ken Inch
Leanne Goodwin
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Becky Evans
Valerie Mahoney
Nicole Ballinger
Michele Bogdanowicz
Jill Clevenger
Gina Borton
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Domenic Scalidone
Jared A. Beard
Mary A. Tietjen
Emma L. Tietjen
Dawn Detweiler
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Marilyn Heffner
Jean Michalec
Robert Cole
Samantha Estrada
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Rachael Cullen
Leah Honig
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Hedgecock
Stacey Sheckler and Bridget
Sola Oluwande
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Sarah Liebhaman
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Julie Steiner
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Lucy Huhn
Sara and Heidi Neeldeeman
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Susan Brodesser
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Samantha Sauerade
Surrin “Butter” and
Gabriel Sheer
Juliette Chamberlain
Nanay Asay
Sarah Alm
Reneso Pulse
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Tara and Leo Laverty
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Morgan Lundy
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Doren Coyne
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Amanda Heller
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Vionate Bontbela
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Alison Wooley

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Jenna Crist
Angela W. and Anthony "Quinn"
V Martin
Barbara Martin
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Colleen Voehoes
Baby Emily
Kelly Haller
Baby Girl McColl
Susan McColl
Baby Girl "Scouter"
Hands Sheffield
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Brettal D.
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Jennifer McCabe

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Amy Huhulin
Hershey Medical Center
Karen Hain
Isabella Florin
Liga Fiorin
Jacob and Kayla Andrew
Jennifer Andrews
James Murphy
Kathy Murphy
Jennifer Reiko Anderson
Terry Ruskaff
Denny Connolly
Mary Connolly
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Jodine Goodman
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Logan Taylor
Allison Gorman
Lucy and Abes
Bonnie Hayes

Clair DeSistoch
Ilse Mindling

My Mother
Nancy Mahoney
Natascha Woods
Chris Woods
Our Mom, Elisabeth, Madeline, Abigail, Maggie, Lily
Jeffrey Schant
Peggy Carr
Jennifer Voss
Devin Melancon
Rammah
Susan Burleson
April Campbell
Rudy Cockson

Suzanne Kelley
Sammy and Zoey
Jennifer Su
Sean Morris
Julie Morris
Taly Morritt
Heather MacPherson
Tino Vitale
Chris Vitale
Todd W.
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Laney Poye
Director of Community Relations
Deb Bush
Director of Marketing & Communications
Julie Allen
Government Relations Manager
Catherine Loisel
Administrative Assistant
Alina Brewer
Research Coordinator

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