

2008 annual report



PREECLAMPSIA
foundation

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About Us faster diagnosis, better care, healthier outcomes

The Preeclampsia Foundation is a 501(c)(3) nonprofit organization whose mission is to reduce maternal and infant illness and death due to preeclampsia. It is dedicated to funding innovative research, raising public awareness, and providing support and education for those whose lives have been touched by preeclampsia, HELLP syndrome and other hypertensive disorders of pregnancy.

What is preeclampsia? what is preeclampsia

Preeclampsia is a disorder that occurs only during pregnancy and the postpartum period, and affects both the mother and the unborn baby.

Affecting 5-8 percent of all pregnancies, it is a rapidly progressive condition characterized by high blood pressure and the presence of protein in the urine. Swelling, sudden weight gain, headaches and changes in vision are important symptoms; however, some women with rapidly advancing disease report few symptoms.

Typically, preeclampsia occurs after 20 weeks gestation (in the late 2nd or 3rd trimesters or middle to late pregnancy), though it can occur earlier. Proper prenatal care is essential to diagnose and manage preeclampsia (sometimes called by its old name, toxemia). HELLP syndrome and eclampsia are other manifestations of the syndrome. It is important to note that research shows that more women die from preeclampsia than eclampsia and one is not necessarily more serious than the other.

Preeclampsia and other hypertensive disorders of pregnancy are a leading global cause of maternal and infant illness and death. By conservative estimates, these disorders are responsible for 76,000 maternal and 500,000 infant deaths each year worldwide.

Building
awareness,
empowering
patients and
improving
outcomes.



Letter from the Chair

letter from the chair

Dear Friends of the Preeclampsia Foundation:

2008 was another productive year for the Preeclampsia Foundation and many of our accomplishments—related to both mission and sound management practices—are highlighted in our Executive Director Eleni Tsigas' letter printed on page 12 of this Annual Report. But despite an intense focus on the Foundation's mission—to reduce maternal and infant illness and death due to preeclampsia—mothers, babies and families continue to suffer from the impact of preeclampsia and other hypertensive disorders of pregnancy.

An estimated 76,000 mothers and 500,000 babies die annually as a result of preeclampsia and, according to experts, preeclampsia is the leading known cause of premature birth, a much publicized condition that can have devastating and life-long consequences. While premature birth—often a direct consequence of preeclampsia—receives almost daily media attention and is the subject of national campaigns aimed at reducing the prevalence of such, making the detrimental effects of such a premature birth widely known and feared, the results of a survey conducted by the Preeclampsia Foundation show that less than half of all pregnant women are educated about the signs and symptoms of preeclampsia. And outside of the at-risk population, significantly fewer than half of the remaining population is familiar with preeclampsia and the risk it poses to pregnant woman and their unborn babies.

This unbalanced focus on the risks of premature birth over the risks of preeclampsia—a primary cause of premature birth—is dangerous. In many instances, a premature birth is the best alternative for the mother and baby and in these instances, management of the preeclampsia must take priority over the goal of delivering a full-term baby. A population educated about and made aware of preeclampsia will mitigate against the overwhelming presumption that only full-term pregnancies are successful and will yield a population capable of understanding that in some instances, a premature birth is the best alternative for both the mother and baby.

The Preeclampsia Foundation's mission focuses on two subjects—the mothers and the babies—and while mothers and babies continue to experience unsafe pregnancies due to preeclampsia and other hypertensive disorders of pregnancy, the Preeclampsia Foundation will continue to push forward with its mission and will continue to advocate on behalf of the mothers, babies and families impacted by this disorder.

Thank you for your continued support,

Leslie Weeks

Leslie Weeks



Leslie Weeks
chair, board of
directors

Preeclampsia is the most common known cause of premature birth and, according to the CDC, premature births are on the rise, having increased by 30 percent since the early 1980s. The incidence of preeclampsia is also on the rise.



Vision Grants

2008 research - vision grants

Vision Grants are small research awards intended to provide initial funding for innovative ideas which might otherwise not be pursued due to lack of funding. Application information for the Vision Grant program is typically available on the Foundation website ([www. preeclampsia.org](http://www.preeclampsia.org)) after the first of each year, with a mid-May deadline for grant submissions. Awards are announced each year at the Saving Grace Gala.

Ödül “Laurie” Amburgey, M.D.

Fellow in Maternal Fetal Medicine

Department of OB/GYN and Reproductive Sciences - University of Vermont / Fletcher Allen Health Care

Women who develop hypertension and have protein in their urine during the second half of pregnancy are at risk for neurological complications including seizures. Seizures are life-threatening and are thought to occur from brain swelling, or edema, resulting from leakiness in the brain and the brain's inability to regulate blood flow. These patients may have substances in their blood that further contribute to brain vessel dysfunction, placing them at high risk for seizures. Dr. Amburgey's experiments will test the effect of plasma from pre-eclamptic women on the functional properties of brain vessels that contribute to the formation of edema.

Daobin Ding, M.D., PhD

Fellow in Maternal Fetal Medicine

Department of OB/GYN - University of Chicago

The etiology of preeclampsia is unknown, though some investigators suggest that a genetic component may play an important role, because there is a higher recurrence rate in patients and their families. Dr. Ding is especially interested in genetics of mitochondria within the placental cells because he believes that mutations there can lead to an overproduction of abnormal oxygen molecules, which can interfere with normal placental development thereby contributing to the onset of preeclampsia. Dr. Ding's research will investigate the role of mitochondrial mutations in preeclampsia.

Alexander Panda M.D., M.P.H.

Pulmonary & Critical Care Medicine

in the School of Medicine - Yale University

Toll-like receptors (TLRs) recognize components of bacteria, viruses and fungi and are critical to the activation of defense against infection. There is evidence that inappropriate activation of the immune system, including TLRs, during pregnancy may contribute to preeclampsia. To address this question, Dr. Panda proposes to characterize TLR function, using methods familiar to their laboratory, in maternal and fetal circulating cells in pregnancies complicated by preeclampsia compared to normal pregnancies. These studies should provide new insights into the regulation of the immune system during pregnancy and preeclampsia, and may also suggest potential drug targets or pathways for new treatments.

“Finding the Preeclampsia Foundation has made a big impact on my life following the early delivery of my daughter in 2002 due to severe preeclampsia that remained even post-partum. It was comforting to know there was a place where others could truly relate to what I experienced ... the lack of understanding, the disappointment, the after-effects. It's now a personal mission of mine to help make some difference in support of the Preeclampsia Foundation's purpose.”

*— Dawn Detweiler
Easton, PA*

Vision Grants cont.

Jonathan T. McGuane, PhD

*Department of Physiology and
Functional Genomics at the
College of Medicine - University of Florida*

Researchers have recently discovered that a placental protein which blocks normal maternal blood vessel function is higher in preeclamptic women. This abnormality causes high blood pressure and decreased blood flow to maternal organs; both characteristics of the disease. Dr. McGuane plans to investigate relaxin, a naturally-occurring hormone that has beneficial actions in pregnancy, and that could directly and indirectly counteract the harmful effects of this placental-derived factor. This could increase blood flow and promote blood vessel health. Thus, relaxin has great potential as a preeclampsia treatment, and could therefore improve maternal/fetal health.

Support

One of our primary missions is to support women and their families through the impact of preeclampsia. Our toll-free hot line (800.665.9341) and e-mail address (info@preeclampsia.org) are two channels of communication that are frequently used. We field about 10-12 calls per month from families that have just been diagnosed.

Every day more than 3,000 people visit the Foundation's website to learn more about the illness, ask questions from the experts, share stories of loss and survival and find out how they can get involved. The website's online forum is buzzing with questions, advice and stories from almost 8,000 members.

symptoms of preeclampsia

High Blood Pressure of 140/90 or higher. A rise in the diastolic (lower number) of 15 or more, or a rise in the systolic (upper number) of 30 or more is cause for concern.

Protein in Your Urine of 300 milligrams in a 24-hour collection or 1+ on the dipstick.

Swelling in the Hands, Feet or Face especially under the eyes, or if an indentation is left when applying thumb pressure. Some swelling is normal in most pregnant women, but sudden swelling is always suspect.

Headaches that won't go away, even after taking medications for them.

Changes in Vision such as double vision, blurriness, flashing lights or auras.

Nausea or Upper Abdominal Pain (epigastric) is sometimes mistaken for indigestion, gallbladder pain or the flu. Nausea late in pregnancy is not normal.

Sudden Weight Gain of 2 pounds or more in 1 week.

Unfortunately, most women have no symptoms until they are very sick. If you have one of these signs or symptoms, see your doctor or go to an emergency room immediately.



Public awareness public awareness & education

The Preeclampsia Foundation has always been of the opinion that an educated woman is a prepared woman. The more women are aware of the signs and symptoms of the disorder, the more women can be proactive and seek qualified care. Research also supports that awareness of warning signs can impact health outcomes.

In 2008, the Foundation continued its brochure campaign aimed at putting accurate information about preeclampsia into the hands of every pregnant woman. For women who have already been diagnosed with the illness, this information will help them know what to expect and empower them to ask more questions. For others, this information will help them understand that preeclampsia exists and educate them on the warning signs and symptoms. During this reporting period, thousands of brochures (English and Spanish), Know the Symptoms magnets and prescription pads were distributed to doctor's offices, clinics and patients.

Recognizing that public awareness is largely driven by what people see and read in the media, we try to be very responsive to media requests for interviews, data or patient stories. We have also leveraged our volunteers to drive awareness through their local media channels.

Preeclampsia consistently ranks as one of the top three causes of maternal mortality.

a sampling of our media coverage during 2008

- ~ **"Expanded 2008 Vision Grant Award Program Announced,"** *PR Newswire delivered by Ascribe, January 4, 2008* – Foundation issued press release announcing increased emphasis on providing funding for innovative preeclampsia-related research.
- ~ **"Opine: Marshall Lindheimer,"** *The University of Chicago Chronicle, January, 24, 2008* – Foundation Medical Board member Dr. Marshall Lindheimer is featured in this article in which he identified the late Leon Chesley, PhD as a renowned scholar in the area of preeclampsia; Lindheimer is a recipient of the Leon Chesley Award for Excellence in the Study of the Hypertensive Disorders of Pregnancy.
- ~ **"Preeclampsia: A Special Report,"** *Pregnancy Magazine, March, 2008* – Foundation supporter Jana Mroczek and Medical Board member Dr. Marshall Lindheimer contributed to this in-depth and informative article about the signs and symptoms of preeclampsia; first-time expectant moms are the author's primary target as many of these women are unfamiliar with the warning signs.
- ~ **"Clue Found to Pregnancy Risk,"** *Winston-Salem Journal, February 12, 2008* – Foundation Medical Board member Dr. Marshall Lindheimer is quoted in this article about new research related to a potential link into the cause of preeclampsia; the Foundation is cited for occurrence-rate statistics.

"After my experience with severe preeclampsia and HELLP Syndrome in 2005, I was so thankful to stumble across the Preeclampsia Foundation's website. It has been such a valuable source of information and support to me after such a difficult and traumatic experience.

— **Melissa Avila-Carroll**
San Jose, CA



a sampling of our media coverage during 2008

- ~ **“March of Dimes Honors the Kraintz Family,”** *Citizens Voice-Wilkes-Barre, Pa., February 24, 2008* - The Foundation is cited for occurrence-rate statistics in this article about a family impacted by preeclampsia.
- ~ **“Carson City Leap Day Baby Wasn’t Due for Another Month,”** *The Daily News, March 6, 2008* - The Foundation is cited for occurrence-rate statistics and basic diagnostic criteria in this article about the premature birth of a baby whose mother developed preeclampsia.
- ~ **“Does Preeclampsia put Women at Higher Risk of Cardiac Problems Later?”** *Health Answers, Boston Globe, March 31, 2008* - The Foundation is cited for occurrence-rate statistics in this article reporting that women who have suffered from preeclampsia are at an increased risk of cardiac problems later in life.
- ~ **“Preeclampsia Awareness Walk Slated at Centennial Park,”** *Quad City Time-Davenport, Iowa, April 10, 2008* - One of several Awareness Walk related articles and broadcasts promoting awareness about preeclampsia and the Foundation; the Mother’s Day weekend walks are hosted by Foundation supporters to raise awareness and money to further the Foundation’s mission.
- ~ **“Hoping to Help Mothers at Risk,”** *Pioneer Press-St. Paul, Minn., May 4, 2008* - Foundation Administrator and supporter Jaime Nolan is featured in this article about a diagnostic test for preeclampsia being developed by Beckman Coulter; Beckman Coulter is a valued supporter of the Foundation.
- ~ **“Lack of Preeclampsia Awareness Increases Risk of Infant Mortality,”** *PR Newswire delivered by Ascribe, May 8, 2008* - Foundation issued press release announcing that survey results indicate that over half of pregnant woman are not informed about the signs and symptoms of preeclampsia and that this lack of awareness translates to worse health outcomes; the incidence of infant death is twice as great for women who give birth prematurely, but were not properly educated by their health care providers.
- ~ **“Awareness Walk Helps Preeclampsia Group,”** *The News & Observer (Raleigh, N.C.), May 11, 2008* - Foundation supporter Elizabeth Willis is quoted in this article about the walk she organized in Raleigh, NC; the Foundation is cited as a source for additional information about preeclampsia.
- ~ **“Awareness Walk helps Preeclampsia Foundation,”** *The Even Sun-Hanover, Pa., May 9, 2008* - One of several Awareness Walk related articles and broadcasts promoting awareness about preeclampsia and the Foundation; the Mother’s Day weekend walks are hosted by Foundation supporters to raise awareness and money to further the Foundation’s mission.
- ~ **“Foundation Supporter Kara Boeldt’s TV Interview,”** *WMTV NBC 15, May 21, 2008* - Informative interview of Foundation supporter Kara Boeldt given to promote her walk and preeclampsia awareness; as a result of said interview, a viewer whose daughter was suffering from postpartum preeclampsia called Mrs. Boeldt seeking additional information about the disorder.
- ~ **“Dietary Fiber Cuts Risk of Pregnancy Complication,”** *U.S. News & World Report, August 21, 2008* - The Foundation is cited for occurrence-rate statistics in this article about the importance of fiber intake by pregnant women.
- ~ **“Preeclampsia Awareness Evening Set for September 20 in Washington D.C.; Event to Focus Attention on Life-threatening Condition Striking 1 in 12 Pregnancies,”** *PR Newswire delivered by Ascribe, August 6, 2008* - Foundation issued press release announcing that CNN’s Elizabeth Cohen will deliver the keynote address at the Foundation’s annual fundraising gala Saving Grace – A Night of Hope chaired by Foundation supporter and past Chair of the Foundation’s Board of Directors Eleni Z. Tsigas.
- ~ **“Preeclampsia Foundation’s ‘Hope Award for Lifetime Achievement’ Goes to Preeclampsia Research Giant,”** *PR Newswire delivered by Ascribe, September 20, 2008* - Foundation issued press release announcing that Medical Board member Dr. James M. Roberts, Senior Scientist and Founding Director of the Magee-Womens Research Institute, was selected to receive the Foundation’s highest honor.
- ~ **“Preeclampsia Foundation Walk for Hannah,”** *Scranton Times-Tribune, September 28, 2008* - One of several Awareness Walk related articles and broadcasts promoting awareness about preeclampsia and the Foundation; the Mother’s Day weekend walks are hosted by Foundation supporters to raise awareness and money to further the Foundation’s mission.
- ~ **“Researchers at Four Major American Universities Receive 2008 Vision Grants: University of Chicago, University of Florida, University of Vermont, Yale University,”** *PR Newswire delivered by Ascribe, September 20, 2008* - Foundation issued press release announcing that Dr. Odul “Laurie” Amburgey, Dr. Daobin Ding, Dr. Jonathan McGuane and Dr. Alexander Panda are the recipients of the 2008 Vision Grants. The Foundation provides Vision Grants to fund medical research pertaining to the pathophysiology, diagnosis, and treatment of hypertensive disorders of pregnancy.
- ~ **“2008 Hope Award for Volunteer of the Year Goes to Science Writer Caryn Rogers; Rogers to be Honored for Dedication and Valuable Service at Annual Benefit Gala,”** *PR Newswire delivered by Ascribe, September 2, 2008* - Foundation supporter and volunteer Caryn Rogers is the subject of this Foundation issued press release announcing Rogers as the recipient of the 2008 Volunteer of the Year Award.
- ~ **“Preeclampsia Foundation, HELLP Syndrome Society Announce Merger,”** *PR Newswire delivered by Ascribe, September 20, 2008* - Foundation issued press release announcing the merger of the HELLP Syndrome Society into the Preeclampsia Foundation, thus consolidating the organizations’ missions and making the Preeclampsia Foundation the only US-based patient advocacy organization focusing on preeclampsia, HELLP Syndrome and other hypertensive disorders of pregnancy.
- ~ **“Pregnancy and Fiber,”** *WTVQ-Lexington, Ky., November 20, 2008* - The Foundation is cited for occurrence-rate statistics in this article about the benefits of fiber for pregnant women.
- ~ **“Mouse Study May Offer Better Diagnosis for Preeclampsia,”** *March of Dimes Foundation, news release, July 27, 2008* - the Foundation is cited as source for additional information about preeclampsia in this article based on a March of Dimes Foundation news release about research being pursued at the University of Texas-Houston Medial School on a potential treatment for preeclampsia.

History of Achievements

history of achievements

NOVEMBER 1999

Preeclampsia Foundation founded.

FEBRUARY 2000

First strategy meeting with Dr. Gordon Perkin, Bill & Melinda Gates Foundation; \$50,000 anonymous pledge; \$12,000 matching funds received.

JUNE 2000

www.preeclampsia.org launched.

MARCH 2001

Preeclampsia Foundation awards two \$15,000 Vision Grants.

APRIL 2001

Appointed to the National Heart Lung and Blood Institute's (NHLBI) Public Interest Research Task Force to help prioritize preeclampsia funding at National Institute of Health (NIH).

JUNE 2001

Partnered with National Institute of Child Health & Human Development (NICHD) to help develop proposal for genetic study using our registered members and the NIH research facilities.

APRIL 2002

Spoke at U.S. Senate Press Conference to introduce SMART Moms Act (Safe Motherhood Act for Research and Treatment), S. 2328/H.R. 4602.

APRIL 2003

Convened the first International Preeclampsia Summit (IPS) in Seattle with a grant from the Bill & Melinda Gates Foundation.

JULY 2003

Issued the Seattle Mandate, an international call-to-action, arising from the IPS.

JULY 2004

Held 1st Annual Preeclampsia Foundation patient conference in Seattle, WA; Participation began in a joint research study with the NIH, National Institute of Child Health & Human Development.

NOVEMBER 2004

Participated in patient advocacy panel at the 14th World Congress of the International Society for the Study of Hypertension in Pregnancy, Vienna, Austria.

MAY 2005

Launched inaugural nationwide Awareness Walk (2,000 walkers in 18 cities) Mother's Day weekend to raise awareness and financial support, surpassing initial goal by nearly 300 percent.

JUNE 2005

Produced patient informational brochure and began distribution to doctors' offices, clinics, patients, etc.; Secured endorsement of Society for Maternal Fetal Medicine for brochure distribution to their membership.

AUGUST 2005

Held 2nd Annual Preeclampsia Foundation patient conference at Oglebay Resort in Wheeling, WV.

SEPTEMBER 2005

Participated in special task force to develop Canadian Perinatal Network, providing early input as a stakeholder, and planning initial and future CPN projects.

NOVEMBER 2005

Successfully launched annual benefit gala—Saving Grace - A Night of Hope—to raise awareness and financial support; Co-sponsored Continuing Medical Education (CME) Seminar: "Preeclampsia Update" with the Deborah E. Powell Center for Women's Health at the University of Minnesota.



DECEMBER 2005

Concluded participation in NICHD research study.

JULY 2006

Hosted Leadership Training Conference to provide training and education to volunteers; Presented results of joint research study with the NIH and NICHD at the 15th World Congress of the International Society for the Study of Hypertension in Pregnancy in Lisbon, Portugal.

SEPTEMBER 2006

Participated as patient advocacy organization in NIH sponsored research workshop aimed at bringing together the top researchers in the field to present their newest work; Formalized an alliance with the March of Dimes (MoD).

OCTOBER 2006

Issued position statement entitled: "Preeclampsia Identifies Women at Risk for Cardiovascular Disease."

NOVEMBER 2006

Translated patient informational brochures into Spanish; Professional Education Committee identified.

FEBRUARY 2007

Participated as patient advocacy organization at the 2007 Society of Maternal Fetal Medicine 27th Annual Meeting in San Francisco, California.

MARCH 2007

Co-sponsored free online CME course: "Heart of a Woman: Pregnancy and Beyond" with the University of MN Deborah E. Powell Center for Women's Health to educate physicians and nurses about preeclampsia diagnoses, management and the ongoing issues related to cardiovascular disease.

MAY 2007

Held 3rd annual nationwide Awareness Walk Mother's Day weekend to raise awareness and financial support to fund mission-oriented tasks.

JUNE 2007

Co-sponsored the North American Society for the Study of Hypertension in Pregnancy's biennial meeting in San Diego, California.

SEPTEMBER 2007

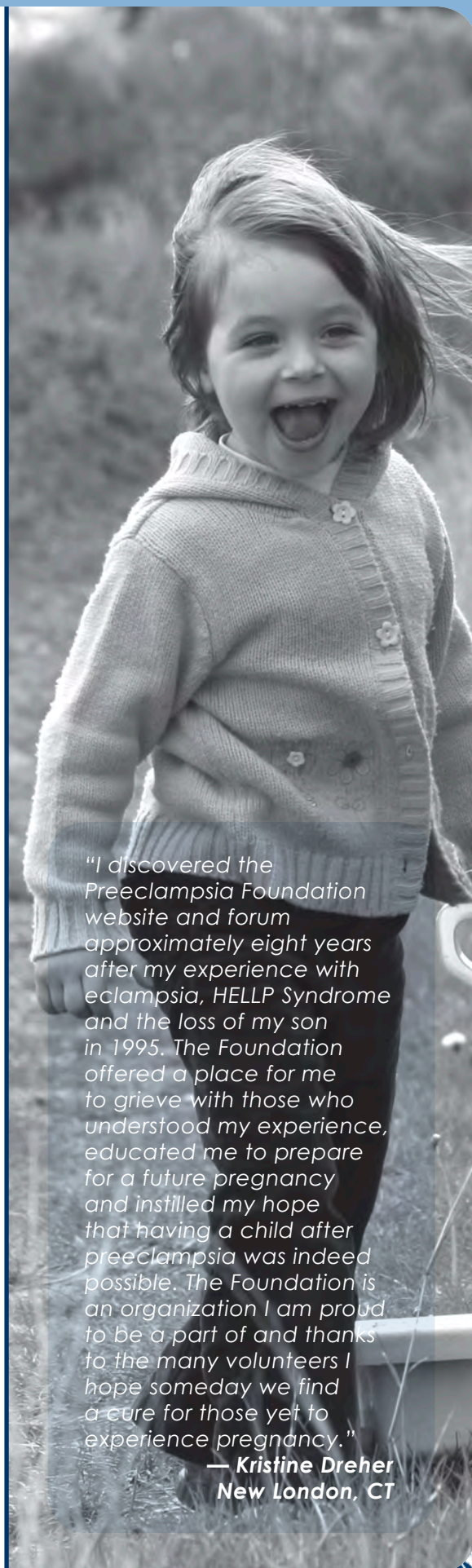
Hired J. Thomas Viall, the Foundation's first experienced executive director; Foundation contributed to the article, "Preeclampsia – A Pressing Problem: An Executive Summary of a National Institute of Child Health and Human Development Workshop," John V. Ilekis, Uma M. Reddy and James M. Roberts *Reproductive Sciences 2007*—a summary compilation of the NICHD preeclampsia workshop held September, 2006.

OCTOBER 2007

Held 3rd annual benefit gala—Saving Grace - A Night of Hope—in Boston, Mass. to raise awareness and financial support; Awarded two \$25,000 Vision Grants to researchers exploring innovative preeclampsia-related research topics.

NOVEMBER 2007

Participated as patient advocacy organization in the Preeclampsia Integrated Estimate of Risk Study Group (PIERS) in Vancouver, British Columbia.



"I discovered the Preeclampsia Foundation website and forum approximately eight years after my experience with eclampsia, HELLP Syndrome and the loss of my son in 1995. The Foundation offered a place for me to grieve with those who understood my experience, educated me to prepare for a future pregnancy and instilled my hope that having a child after preeclampsia was indeed possible. The Foundation is an organization I am proud to be a part of and thanks to the many volunteers I hope someday we find a cure for those yet to experience pregnancy."

**— Kristine Dreher
New London, CT**



2008 Milestones

2008 milestones

MAY

Preeclampsia Awareness Month, marked by new survey findings and about ten Awareness Walks held across the country.

New survey results released by the Preeclampsia Foundation indicate that over half of pregnant women are not informed about the signs and symptoms of preeclampsia, a life-threatening condition that complicates one in twelve pregnancies. This lack of awareness translates to worse health outcomes; the incidence of infant death is twice as great for women who give birth prematurely, but were not properly educated by their health care providers.

JUNE

Wisconsin volunteers coordinate professional education event for the Perinatal Conference at Meriter Hospital to encourage patient provider partnerships.

The Foundation participates in Surgeon General's Conference on the Prevention of Preterm Birth, registering complaint that preeclampsia seems to have been relegated to "research wasteland" by its glaring omission from the proceedings, despite its status as the No. 1 known cause of prematurity.

SEPTEMBER

New Awareness DVD premieres at Saving Grace 2008. This 22 minute documentary style DVD produced by Etheridge & Co. highlights various women's stories, medical information, signs & symptoms, and risk factors. It is intended for public distribution and to support volunteer's efforts to spread awareness and life-saving information.

Saving Grace - A Night of Hope, in Washington, DC, signals Foundation's interest in advocacy and international impact of preeclampsia. 13 Congressional honorary co-chairs, a beautiful original art display by the World Health Organization, and cooperation with the biennial global conference of the International Society for the Study of Hypertension in Pregnancy (ISSHP), including a welcome from the Society's president set the stage for another successful gala.

Caryn Rogers honored as Volunteer of the Year. Community Forum moderator keeps up with new preeclampsia research, summarizing complex material so the non-scientist can understand what it means.

Preeclampsia Foundation and HELLP Syndrome Society made the decision to merge their organizations, announcing this news at Saving Grace on September 20. The merger will go into effect January 1, 2009.

A record number of Vision Grants were awarded, following the strongest field of submissions to date. \$100,000 was awarded to four young investigators:

Dr. Odul (Laurie) Amburgey, University of Vermont

Dr. Daobin (David) Ding, University of Chicago

Dr. Jonathan McGuane, University of Florida

Dr. Alexander Panda, Yale University

Dr. James Roberts recognized for notable contributions to research and advancement of our understanding of preeclampsia with the Foundation's Hope Award for Lifetime Achievement at Saving Grace.

Awareness Study accepted for poster presentation at ISSHP's global medical conference in Washington, DC, Sept. 20-24.

SEPTEMBER - DECEMBER

After years of administrative progress and certified national presence, the Foundation was finally accepted into the Combined Federal Campaign (CFC), the world's largest workplace charity drive

"The Preeclampsia Foundation introduced me to a network of people locally and through the forum that were a huge source of support to my husband and I after we lost our son to preeclampsia in 2004. I received the support, information on this disease, and comfort I needed in my time of grief, and am now giving back by providing comfort and information on preeclampsia to others as well as organizing fundraising activities for this incredible Foundation."

— **Miranda Childers**
Minneapolis, MN

administered by the Federal Office of Personnel Management. This allows any employee of the federal government anywhere in the country to select the Preeclampsia Foundation as its designated charity for workplace donations.

ONGOING

Preeclampsia Foundation website the No. 1 source of online information on the topic. Total new posts in the community forum 52,181 Total new members joining the active online community 1,157.

Fundraising program undergoes more formal development with production of fundraising guides for volunteers wishing to get involved via numerous types of events and activities.

Several volunteers held various fundraisers such as jewelry sales, soap and lotion sales, independent Awareness Walks, and golf tournaments, raising over \$20,000.

In the U.S., 25 percent of all cases of preeclampsia are categorized as severe.

Looking Ahead

looking ahead

Key focus areas for 2009 include

- Redevelop our website to reach even greater numbers of patients, providers and supporters through updated content and functionality, new social networking technologies and stronger branding and outreach.
- Develop a Talent Management program to more fully utilize the skills and passion of our volunteers toward fulfillment of our mission.
- Reach more health care providers including nurses, midwives and childbirth educators, along with physicians, encouraging the use of our patient education materials and improving provider-patient communications.
- Use low literacy research to increase the quality and appropriateness of our patient education tools for all literacy levels.
- Develop experiential and other learning tools for health care providers.
- Research and develop a roadmap for international and advocacy programs.
- Drive more member-participant research studies.
- Increase the number of local fundraising events.
- Launch an Education & Awareness Grants program to support local education programs with small funding grants.





Eleni Tsigas
executive director

*Based on the figure of 5 to
8% of all pregnancies in the
US developing preeclampsia
... as many as 40 women are
diagnosed with preeclampsia
every hour of every day.*

Executive Director letter from the executive director

Dear Friends:

Even as we face trying economic times, it is especially critical that the Preeclampsia Foundation ensure fiscal responsibility and sustainability as an organization. Although charitable organizations are stretched thinner than ever these days, our mission hasn't diminished one iota – mothers are still having babies and one out of 12 of them are suffering from preeclampsia, HELLP syndrome and related hypertensive disorders of pregnancy.

I am pleased to report that our 2008 audit passed the scrutiny of the independent auditing firm of Blanski Peter Kronlage & Zoch, P.A. Certified Public Accountants reviewed both our books and procedures and have found no material deficiencies. Our books are accurate and our management policies sound.

Many of our accomplishments last year supported our fiscal and management goals. For example, we had another record-breaking year for our national Awareness Walks—securing participants in 17 locations across the country, raising over \$75,000 and reaching tens of thousands of citizens with our critical messages about preeclampsia awareness and information.

Our annual benefit gala, Saving Grace - A Night of Hope, was held in Washington, DC, in conjunction with the international scientific conference (ISSHP) on preeclampsia. This coordination was an important gesture as the Foundation begins taking a larger role on the international stage. It was also an important first step as we began reaching out to legislators and other key federal agencies to lay the groundwork for a concerted advocacy program. Almost a dozen senators and congressmen signed on as honorary co-chairs for the gala. One of the most rewarding elements of the evening was being able to present four research grants, totaling \$100,000, to deserving young investigators.

The cornerstone of 2008 was producing our first documentary, *If Only We Knew – The Quest to Conquer Preeclampsia*. That it went on to win a prestigious CINE award was a bonus. This documentary is an important element in our Education & Awareness toolkit. Research has shown, ours included, that pregnant women are not routinely educated about the signs and symptoms of preeclampsia and that this lack of information has a disastrous impact on health outcomes when this illness does strike. Our public awareness survey, conducted midyear, produced nearly 1,400 responses, and statistically corroborated what we have known anecdotally for years.

Thus, our 2009-2010 initiatives will be strongly focused on this area of patient education. We are intent on being successful at both ends of the literacy and health access spectrum. One program will develop an educational handout suitable for patients at all literacy levels.

Analysis of our website has shown that it is, by far, the most sought after source of information on the topic. Nearly 3,000 new visitors are coming to our virtual headquarters every day. Our primary programmatic initiative in 2009-2010 is to bring our technology and online functionality up-to-date, improve the user experience and drive even more of this critical information into the right hands. We will also use the website to help mobilize scores of volunteers to make a difference for the cause.

Shattering myths and disrupting the status quo—these are our rallying cries for the next several years. Please partner with us for this incredibly meaningful work. Together, we are making a difference!

Eleni Tsigas

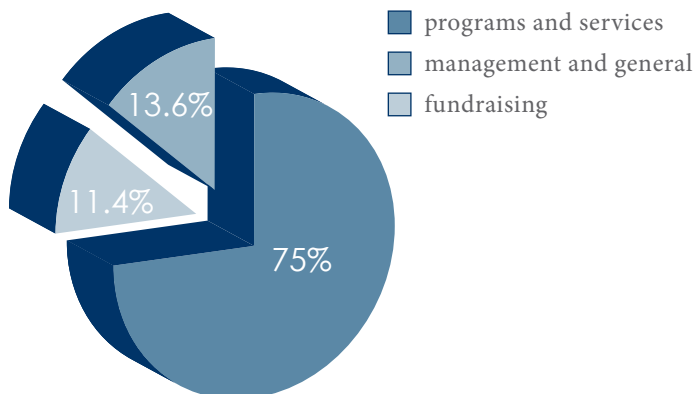
Eleni Tsigas

Statement of Activities

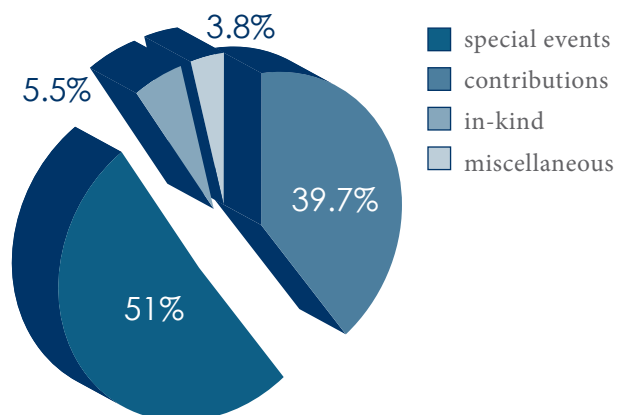
statement of activities year ended december 31, 2008

	Unrestricted	Temporarily Restricted	Total
PUBLIC SUPPORT AND REVENUE			
Contributions	137,040	4,115	141,155
Contributed services	719	-	719
In-kind contributions	-	-	-
Interest income	12,624	-	12,624
Miscellaneous income	226	-	226
	<u>\$150,609</u>	<u>\$4,115</u>	<u>\$154,724</u>
SPECIAL EVENTS			
Revenue	50,220	-	50,220
Contributions	177,146	-	177,146
In-kind contributions	19,500	-	19,500
Event expenses	(46,293)	-	(46,293)
	<u>\$200,573</u>	<u>\$-</u>	<u>\$200,573</u>
NET ASSETS RELEASED FROM RESTRICTION			
Satisfaction of restriction	78,625	(78,625)	-
Total support and revenue	<u>\$429,807</u>	<u>\$(74,510)</u>	<u>\$355,297</u>
FUNCTIONAL EXPENSES			
Programs and services	442,342	-	442,342
Management and general	80,599	-	80,599
Fundraising	67,376	-	67,376
	<u>\$590,317</u>	<u>\$-</u>	<u>\$590,317</u>
CHANGE IN NET ASSETS	<u>\$(160,510)</u>	<u>\$(74,510)</u>	<u>\$(235,020)</u>
NET ASSETS, BEGINNING OF YEAR	<u>\$696,860</u>	<u>\$93,625</u>	<u>\$790,485</u>
NET ASSETS, END OF YEAR	<u>\$536,350</u>	<u>\$19,115</u>	<u>\$555,465</u>

functional expenses:



revenue sources:



Awareness Walks

awareness walks bring in \$70,000+

Pre-event flooding, competition from other events, and dreadful day-of weather were all challenges faced—and overcome—by organizers of the 2008 Awareness Walks held in May. Walks in Stahlstown, Pa.; Research Triangle, N.C.; Davenport, Iowa; Madison, Wis.; Minneapolis, Minn.; Tooele, Utah; San Diego, Calif.; in addition to other individual Friends and Family Walks netted more than \$70,000 for the Preeclampsia Foundation. Five of the formal walks held were either first- or second-year events. Organizers of these emerging events learned lessons that will aid them and other would-be organizers in future planning.

Research Triangle, N.C., coordinator Elisabeth Willis, a high school student herself, was pleased that they secured excellent media coverage and were able to reach a lot of high school students, which she feels can only promise them a safer future parenthood.

Pennsylvania organizer Kelly Licari commented on her second-year event by saying, “It may not have been the largest, but if sharing our stories prevents just one family from going through what we’ve gone through, then it was worth every moment.” Licari added, “If it prevents more than one tragedy, then that’s even better!”

Stephanie Steiner of Springfield, N.J. who held a Friends and Family walk e-mailed her story to everyone she knew. “That helps raise awareness and, in turn, funds. Even though my relatives and close friends knew I had preeclampsia, many forgot the details and newer friends didn’t know the details. I raised a lot of money in the week prior to the Walk,” Steiner said.

Cynthia Hamilton of Tooele, Utah, shared, “Hosting the walk was a wonderful and moving experience. Personally for me it was an opportunity to ‘pay it forward.’” Beyond the walk itself, Hamilton’s team distributed information about preeclampsia, the Foundation, and the upcoming walk at a local Healthy Woman Conference with an audience of 500 people.

Due to spring flooding, John and Brenda Warner, organizers of the Davenport, Iowa, walk were forced to find a new location less than 2 weeks before the event but were able to transplant the event from a riverfront location to the near-downtown Brady Street Stadium. The temporary setback, however, yielded a partnership with the stadium’s owners that may result in a permanent home for future walks in Davenport. Passersby on Brady Street witnessed a parade of walkers going into the stadium, balloons, local sport team mascots, and even the Oscar Meyer Weinermobile. The Warners are most proud of the live media coverage from three local television stations and a 350+ person turnout, even after the last-minute relocation. The Davenport walk was the fourth walk for the city and the third for the Warners and it garnered some attention as a result of Iowa Governor Chet Culver who proclaimed May as Preeclampsia Awareness Month. Culver has a personal connection to the cause through his wife, Mari, who is a preeclampsia survivor.

Walk proceeds support the Foundation’s research grants and development of education and awareness tools and services.



Saving Grace saving grace - a night of hope

At Saving Grace - A Night of Hope gala on September 20, 2008, the Preeclampsia Foundation featured the premiere of its new educational DVD. With the twenty-two minute DVD, *If Only We Knew... The Quest to Conquer Preeclampsia*, the Foundation strives to reach out to the public and promote awareness of this life-threatening health issue.

“The key is to get the information out,” said Eleni Tsigas, executive director of the Preeclampsia Foundation. “Awareness can save lives. There is often correlation between lack of preeclampsia information and a pregnancy’s negative outcome.”

Despite being a potentially devastating disease, and not terribly uncommon, preeclampsia is given little public attention and little government research funding. In an effort to inform the public, the Preeclampsia Foundation planned to develop an educational DVD and, thanks to donors, the funding became available in 2007.

“Of course, we have the website and the brochure, and we support the importance of patient-provider communication, but we also want something that is emotional and engaging,” said Tsigas.

The DVD is now available at the Foundation’s website. Campaign volunteers can request the DVD free of charge if they plan to use it for community education and outreach. The Foundation hopes volunteers will help spread the information contained in the DVD at various programs and events such as Awareness Walks, libraries, women’s groups, sororities, local cable access TV channels, and even local network news and programming.

An 8 minute version of the DVD is posted on YouTube (www.youtube.com).

*The night was amazing. I was truly moved
by the personal stories and hearing of all the
unbelievable research so many are doing.*

- Saving Grace 2008 Attendee



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Dr. Thomas R. Easterling University of Washington School of Medicine

Dr. Easterling received his M.D. from University of North Carolina Medical School. He is a national expert in the field of hypertension in pregnancy. A professor at the University of Washington Medical School, Dr. Easterling has received numerous awards including: the Young Investigator's Award of the International Society for the Study of Hypertension in Pregnancy, the Society Award for the Society of Perinatal Obstetricians for research on the hemodynamics of preeclampsia, and was honored by the journal *Obstetrics & Gynecology* for conducting one of the four most significant studies of 1999 regarding early antihypertensive treatment to prevent preeclampsia. He and his team at the University of Washington are members of the NIH-sponsored Obstetrical Pharmacological Research Unit network investigating the use of medications in pregnancy. Dr. Easterling continues an active clinical and research practice at the University of Washington and serves as the Director of the Preeclampsia Foundation's Medical Board.

Dr. Phyllis August Weill Cornell Medical College

Since 1996, Dr. August has been the chief of the Division of Hypertension and the Cardiovascular Center and a professor of medicine at Cornell University's Weill Medical College. A 1977 graduate of the Yale Medical School, she did her residency in internal medicine and her fellowship in nephrology and hypertension at the New York Hospital-Cornell Medical

Center. She is also a practicing physician who brings much clinical evidence to her study of hypertension in pregnancy.

Dr. Peter Von Dadelszen University of British Columbia

Dr. Peter von Dadelszen is a consulting perinatologist at Children's and Women's Health Centre of British Columbia (CWHC) and an Assistant Professor of Obstetrics and Gynecology (Maternal-Fetal Medicine) at the University of British Columbia (UBC), where his appointment is as a clinician-scientist, with 60 percent of his time dedicated to preeclampsia and pregnancy hypertension research—from basic science to clinical epidemiology. He is currently investigating mechanisms involved in the development of preeclampsia, as well as a possible disease modifying therapy. Dr. von Dadelszen is the immediate - past president of the North American Society for the Study of Hypertension in Pregnancy (NASSHP) and President of ERIPED (Equipe de Recherche Interdisciplinaire sur la Pre-Eclampsie et ses Determinants), Canada's preeclampsia research alliance.

Dr. Ananth Karumanchi Beth Israel Deaconess Medical Center, Harvard Medical School

Dr. S. Ananth Karumanchi is associate professor of medicine at Harvard Medical School and an attending physician in the Nephrology and Molecular and Vascular Medicine Divisions at the Beth Israel Deaconess Medical Center. He holds a second appointment as a Senior Scientist with the Department of Obstetrics and Gynecology at the Beth Israel Deaconess Medical Center. He

received his M.D. from the University of Madras, Chennai, India. He is a recipient of the Carl W. Gottschalk Research Scholar Award from the American Society of Nephrology, the Hope Award from the Preeclampsia Foundation, the Young Scholar Award from the American Society of Hypertension, and recently (October, 2007) named a Howard Hughes Medical Investigator.

Dr. Marshall Lindheimer University of Chicago

Dr. Lindheimer, a Board Certified internist and nephrologist, is a professor emeritus in the Departments of Medicine and Obstetrics and Gynecology at the University of Chicago. His clinical interests focus on the management of pregnant women with kidney disease and hypertension, while his research career has stressed renal physiology, volume homeostasis, and blood pressure control in normal and abnormal pregnancy. He is also a consultant to the World Health Organization, participating in their Global Program to Conquer Preeclampsia, and advising them in the areas of clinical trials and the implementation of best care policies in developing nations.

Dr. Lindheimer is one of the founders of the International Society for the Study of Hypertension in Pregnancy, and has served both as its secretary treasurer and president. His 350 plus publications include seminal basic science observations, clinical studies, numerous text chapters and author- or editorship of seven texts, including the most recent editions of Chesley's *Hypertensive Disorders in Pregnancy*, and Barron & Lindheimer's *Medical Disorders During Pregnancy*.

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Dr. James N. Martin, Jr.

Wiser Hospital for Women and Infants University of Mississippi Medical Center

Dr. Martin is a professor of Ob/Gyn, director of the division of Maternal-Fetal Medicine, and chief of Obstetrics for the Wiser Hospital for Women and Infants at the University of Mississippi Medical Center. His clinical expertise lies in the management of complicated pregnancies, particularly related to hypertensive disorders. Dr. Martin is the author of more than 400 scientific communications, many which address issues related to preeclampsia-eclampsia and atypical forms of this disease such as HELLP syndrome. He is one of the founders and a past president of The North American Society for the Study of Hypertension in Pregnancy, is past president of the Society for Maternal-Fetal Medicine, and is secretary of ACOG National. His research in hypertensive disorders of pregnancy began during his residency training at the University of North Carolina Hospitals and continued while completing a fellowship in maternal fetal medicine at Texas Southwestern/ Parkland Hospital in Dallas, Texas.

Dr. Suzanne Oparil

University of Alabama School of Medicine in Birmingham

Dr. Suzanne Oparil is professor of medicine and of physiology and biophysics at the University of Alabama School of Medicine in Birmingham, where she is also director of the Vascular Biology and Hypertension program.

She is a past president of the American Society of Hypertension, the American Heart Association and the first woman past - president of the American Federation for Medical Research. She also has leadership roles in the Association of American Physicians, American Society for Clinical Investigation, Southern Society for Clinical Investigation, American Physiological Society, Clinical Physiology Advisory Committee, and Inter-American Society of Hypertension.

Dr. Oparil has a career interest in the fundamental mechanisms of cardiovascular disease and in using the information to develop novel treatments. She is author and coauthor of more than 1,000 abstracts, book chapters, and journal articles in circulation,

New England Journal of Medicine and American Journal of Hypertension, as well as others.

Dr. John T. Repke

Milton S. Hershey Medical Center Penn State College of Medicine

Dr. Repke is a professor and chairman of the Department of Obstetrics and Gynecology at the Penn State College of Medicine – Milton S. Hershey Medical Center. He is a nationally recognized expert in maternal/fetal medicine and is listed in “Best Doctors in America.” His expertise is in the study of prevention and management of hypertension in pregnancy and preeclampsia. In addition to editing a textbook on obstetrics, Dr. Repke has published over 135 research articles in peer-reviewed journals and over 50 review articles and book chapters. He is a past president of the North American Society for the Study of Hypertension in Pregnancy.

Dr. James M. Roberts

Magee-Women's Research Institute University of Pittsburgh School of Medicine

Dr. Roberts is professor and vice chair for research in the Department of Obstetrics, Gynecology, and Reproductive Sciences at the University of Pittsburgh School of Medicine, and director of Magee-Women's Research Institute. Dr. Roberts has received national and international recognition for his work on preeclampsia. He was the recipient of the Chesley Award for lifetime achievement in the study of hypertension in pregnancy, is the author of more than 160 publications and is a reviewer for numerous medical and scientific journals. He has served on scientific review boards of the National Institutes of Health, the Medical Research Council of Canada, the Food and Drug Administration and the March of Dimes. He has held posts with the NICHD Maternal Fetal Medicine Network, the Canadian Institute of Health Sciences Research, the Perinatal Research Society, the North American Society for the Study of Hypertension in Pregnancy, the Society of Gynecological Investigation and the International Society for the Study of Hypertension in Pregnancy.

Dr. Baha M. Sibai

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Dr. Sibai is professor and chairman of the Department of Obstetrics and Gynecology at the University of Cincinnati College of Medicine. His academic leadership and contributions to research in the dissection of the hypertensive diseases of pregnancy and other basic problems associated with obstetrics and gynecology has awarded him national and international recognition in the field of Maternal-Fetal Medicine, particularly in the area of hypertension in pregnancy. His contributions have organized the treatment plans of many physicians. Dr. Sibai's international notoriety in preeclampsia and eclampsia evolved as a result of his authorship or co-authorship of over 350 peer-reviewed publications in national and internationally circulated publications.

Dr. Denise Raynor

Emory University President, North American Society for the Study of Hypertension in Pregnancy

Dr. Raynor is professor emeritus in the Department of Obstetrics and Gynecology at Emory School of Medicine. Now on leave of absence, she is studying for an MPH at the Harvard School of Public Health. Dr. Raynor received her MD from Vanderbilt University and completed her residency at Thomas Jefferson University. After general Ob/Gyn practice in rural North Carolina, she completed her Maternal-Fetal Medicine fellowship at the University of Florida and then joined the faculty at Emory in 1994. Dr. Raynor has been the residency program director, director of the Ultrasound Division, and the Perinatal Center at Grady Memorial Hospital. For Dr. Raynor, her role as an educator has been important and she continues to mentor numerous residents and fellows, both past and present. Her research has included both basic and clinical studies in preeclampsia as well as fetal behavior, prenatal diagnosis, and pregnancy subsequent to cesarean with numerous publications.

Hope Award 2008 hope award - volunteer of the year

Caryn Rogers, a moderator on the Preeclampsia Foundation's community forum for 3 years who has written well over 4,500 posts, has a unique writing ability. She explains science and biological mechanisms by providing straightforward summaries of the current understanding of preeclampsia and related disorders. Rogers was recognized as the 2008 Volunteer of the Year.

She is tireless in keeping up with new research and she summarizes incredibly complex material so the non-scientist can understand what it means . . . and she's always there to answer a question if someone doesn't understand.

Rogers grew up and went to college in Arizona and recently moved to Mt. Lebanon, PA. She is a bit of a Renaissance Woman in that she has been a private tutor in mathematics, played violin with the Symphony of the Southwest for more than 7 years, and is a freelance architectural drafter.

Rogers is also a preeclampsia survivor. Her son, Oscar, was born at 34 weeks following a diagnosis of severe preeclampsia. It was then that she learned of the Preeclampsia Foundation and became active on the Forum. Caryn eventually took on the role of "science writer" and the rest—as they say, is history.

Her self-deprecating sense of humor is illustrated in her signature on all her forum posts: "Caryn, who is not a doctor and who talks about science stuff way too much."

The Preeclampsia Foundation is thankful that she does!

Hope Award 2008 hope award - lifetime achievement

Dr. James M. Roberts, senior scientist and founding director of the Magee-Women Research Institute (Pittsburgh, PA) was presented the Hope Award for Lifetime Achievement on September 20 in Washington, DC.

Dr. Roberts has made numerous contributions over a lifetime of research dedicated to preeclampsia. His investigation into certain cell behavior (endothelial cells) as an important contributor to the development of preeclampsia as well as his work with Dr. Carl Hubel on the role of oxidative stress in preeclampsia have radically changed thinking about preeclampsia. More recently he has championed the "two stage" hypothesis, suggesting that preeclampsia is the result of a unique interaction of co-existing maternal and placental conditions. Dr. Roberts' laboratory is investigating the role obesity plays in the development of preeclampsia and the notion that maternal conditions that lead to preeclampsia also increase risk of cardiovascular disease in later life.

Ms. Leslie Weeks, chair of the Preeclampsia Foundation Board, stated, "Add to these accomplishments his role in establishing Magee Womens Research Institute, one of the only health centers in this country that places great emphasis on preeclampsia investigation, and it is evident why his selection to receive this honor was an easy, yet important decision."

Dr. Roberts is a member of the highly respected Institute of Medicine of the National Academy of Sciences, as well as having served in various leadership roles for numerous other professional societies.



2008 Hope Award recipient
Dr. James M. Roberts (left) for
lifetime achievement.

2008 Hope Award recipient
Caryn Rogers (right) for
volunteer of the year.

*A severe form of preeclampsia
(HELLP) may lead to
seizures, stroke, and major
organ failure.*



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