



P R E E C L A M P S I A
foundation

Organization Fact Sheet

Overview

The Preeclampsia Foundation is a U.S.-based 501(c)(3) non-profit organization established in the year 2000 to fund and drive research, raise public and professional awareness, and provide support and education for those whose lives have been touched by preeclampsia and other hypertensive disorders of pregnancy. Its mission is to stop preventable death and disability of mothers and babies by eliminating delays in diagnosis, implementing the best known practices, developing new practices, and helping women and their families through the impact of preeclampsia. It is the only organization in North America that represents the voices of patients affected by hypertensive disorders of pregnancy such as preeclampsia and HELLP Syndrome.

The advocacy group was established by a few individuals who had been either affected by preeclampsia or involved in studying or treating the disease. Internationally known medical experts on preeclampsia joined the medical board within the first few months of the foundation's inception to help participate in world health advocacy, advance research and development, increase public awareness efforts, and to provide accurate medical guidance for the myriad women seeking the latest information.

Funding partners and sources for the foundation have come from a variety of resources including individual pledges and grants from maternal health, life science and corporate organizations such as the Bill & Melinda Gates Foundation, Apex Foundation, Microsoft Corporation, Johnson & Johnson and Beckman Coulter.

Highlights (2000-2009)

- Online forum has almost 7,200 members with over 275,000 posts (February 2009); website routinely gets about 6 million hits per month; over 75 active volunteers engaged in fundraising, education and patient support across the continent.
- The HELLP Syndrome Society merges with the Preeclampsia Foundation to create stronger, unified voice for all patients with hypertensive disorders of pregnancy, January 2009.
- Developed new organization staffing model; Eleni Z. Tsigas hired as Executive Director, January 2009
- Produced patient informational brochures (in English and Spanish) and began distribution to doctor's offices, clinics, patients, etc. (57,000 gone out thus far); secured endorsement of Society for Maternal Fetal Medicine for distribution to their membership as well as the national network of Women's Centers of Excellence, June 2005-ongoing
- Produced 20-minute CINE Award-winning awareness DVD, debuted at *Saving Grace - A Night of Hope* in Washington, DC, September 2008.
- 4th annual benefit gala – *Saving Grace - A Night of Hope* – was held in Washington, DC with keynote speaker Elizabeth Cohen, Senior Medical Correspondent for CNN; Foundation awarded four Vision Grants totaling \$100,000 for new research initiatives, September 2008.

- Represented preeclampsia perspective at Surgeon General's Conference on Prevention of Preterm Birth; issued call-to-action for greater attention on preeclampsia as leading cause of preterm birth, June 2008.
- Results of first awareness survey conducted by the Foundation indicate low rate of patient education provided by most care providers, and high correlation between inadequate knowledge of preeclampsia signs & symptoms and poor pregnancy outcomes, May 2008.
- Combined Federal Campaign (CFC) accepts Preeclampsia Foundation, Spring 2008.
- Financially supported and participated in Preeclampsia Integrated Estimate of Risk (PIERS) Study Group in Vancouver, British Columbia, November 2007.
- 3rd annual benefit gala – *Saving Grace - A Night of Hope* – with keynote speaker Dr. Benjamin Sachs, held in Boston, MA, October 2007.
- Hired first professional Executive Director, J. Thomas Viall, September 2007.
- Presented patient perspective on gaps in preeclampsia research at National Institute of Child Health & Human Development workshop, September 2007. Workshop findings published in *Reproductive Sciences*, Vol. 14, No. 6, 508-523 (2007).
- 2nd annual benefit gala – *Saving Grace - A Night of Hope* – with co-chair Bill Weldon, Chairman & CEO of Johnson & Johnson, held in San Francisco, CA, October 2006.
- Developed position statement on long term health impact of preeclampsia entitled: “Heart of a Woman: Pregnancy and Beyond”; presented at NIH, various professional education classes, and other venues
- Produced online CME course for medical professionals: “Heart of a Woman: Pregnancy and Beyond” to educate health care providers about preeclampsia diagnoses, management and the ongoing issues related to cardiovascular disease, available online 2007-2008.
- Nationwide walk-a-thons held five consecutive years (2005-2008) in numerous cities in the U.S. and Canada, raising awareness and financial support.
- Successfully launched annual benefit gala – *Saving Grace: A Night of Hope* – to raise awareness and financial support, Minneapolis, MN, November 2005
- Participated in special task force to develop Canadian Perinatal Network, September 2005
- Held 2nd Annual Preeclampsia Foundation patient conference at Oglebay Resort in Wheeling, WV, August 2005
- Launched inaugural nationwide walk-a-thon (2,000 walkers in 18 cities) Mother's Day weekend to raise awareness and financial support, May 2005
- Presented patient advocacy workshop at the 14th World Congress of the International Society for the Study of Hypertension in Pregnancy, Vienna, Austria, November 2004
- Held 1st Annual Preeclampsia Foundation patient conference in Seattle, July 2004
- Participating in a joint research study with the National Institute of Health (NIH), National Institute of Child Health & Human Development (NICHD), 2004-2005
- Received significant grants from the Apex Foundation earmarked for development and special projects, November 2000, March 2001, November 2004
- Received the Dulcian, Inc. grant for development of the National Preeclampsia Registry, August 2003 (production model nearing completion after early technical challenges met).
- Received Bill & Melinda Gates Foundation grant to convene first International Preeclampsia Summit in Seattle, April 2003
- Received significant private donation to improve online information sharing among patients, February 2003
- Spoke at U.S. Senate Press Conference to introduce S.M.A.R.T (Safe Motherhood Act for Research and Treatment), S. 2328/H.R. 4602, April 2002
- Appointed to NIH's National Heart Lung and Blood Institute (NHLBI) Public Interest Research Task Force to help prioritize preeclampsia funding at NIH, April 2001

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Resources & Contact Information

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