

# Advocacy is essential to supporting women with pre-eclampsia

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## Abstract

Advocacy has a critical role in advancing the maternal health agenda. Patient advocacy groups can hold governments and other stakeholders accountable and ensure that commitments are translated into concrete action. This article highlights the advocacy efforts of the Preeclampsia Foundation, a patient advocacy organisation that aims to improve the diagnosis, management, and prevention of pre-eclampsia through research and improved healthcare practices. A number of challenges continue to face maternal health advocacy especially in low- and middle-income countries. Future directions include developing a strategic focus for advocacy, effectively engaging citizens to build a culture of accountability, and monitoring and evaluation of advocacy efforts.

## Keywords

Advocacy, maternal health, patient groups, pre-eclampsia

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Over the past 30 years, patient advocacy organisations like the Preeclampsia Foundation have incorporated advocacy and efforts to change public policy into their missions and principal activities, and they have seen the gains that can be attained through such initiatives. Patient advocacy organisations are recognising that having their views and priorities addressed by policymakers is aided by engaging patients and families in policy advocacy, in addition to engaging clinicians, scientists, and researchers.

Advocacy is an organised, deliberate, systematic, and strategic process intended to bring about a new or revised social or economic policy or programme.<sup>1</sup> In this article, we define advocacy as put forth by Cohen et al.,<sup>2</sup> as ‘the pursuit of influencing outcomes – including public policy and resource allocation decisions within political, economic, and social systems and institutions – that directly affect people’s current lives’. Advocacy plays a critical role in ensuring that commitments translate into concrete action, and patient advocacy groups can hold governments and other stakeholders accountable to regional, national, and global commitments by demanding that policies are reformed, funds invested and tracked, and health outcomes measured and published.<sup>1</sup>

Individual patient advocacy can take many forms that allow individuals to choose whatever level of involvement is appropriate for them. Examples include:

- placing phone calls or sending emails to offices of elected officials to either voice support for or opposition to a particular policy, or call for greater investment in a disease or condition;
- posting an item on Facebook;
- tweeting a message through Twitter;
- submitting a letter-to-the-editor or an opinion piece to a newspaper or on-line media forum;
- attending a town hall meeting or other public forum where policy issues are discussed;
- meeting with elected officials;
- hosting briefings and other policy forums where elected officials can learn about a specific condition and understand the role that they can play in reducing the adverse impact of the condition in question on women and their children;
- serving on patient advisory councils within various healthcare settings.

Clinicians, researchers, and other medical professionals must also participate in advocacy efforts. Raising awareness about gaps in care

and resources can lead professional organisations to create or adopt protocols and other management tools as we move towards a shared goal of providing consistent, quality care for women with medical complications of pregnancy and their babies.

Patient advocacy organisations are often classified under civil society. Civil society is defined as ‘the social arena that exists between the state and citizen, and is not part of the state or the market (for-profit sector)’.<sup>3</sup> Civil society organisations are not homogenous but have varying levels of engagement with the government and a range of institutional capacities. They include the family and private sphere as well as community groups and non-governmental organisations (NGOs). What they all have in common is that they are not operated by the government and they are not businesses (i.e., run for profit), and they are usually run by volunteers and reliant on donations. These organisations provide a way for shared needs and interests to be satisfied.<sup>1</sup> In maternal health, for example, the White Ribbon Alliance is an informal coalition of NGOs, donors, and their global partners who strive to make safe motherhood a priority globally.<sup>4</sup> Over the years, thousands of individuals and organisations have joined the White Ribbon Alliance resulting in 13 countries that have established National Alliances. Perhaps, the most impressive and impactful advocacy effort was that of a 2002 White Ribbon Alliance march to the Taj Mahal (India), an iconic memorial to the Shah’s young wife who died in childbirth. The march attracted thousands of supporters, celebrities, ordinary women, health workers, and the media. This resulted in a change in policies by gaining political attention and priority. Policies were changed to allow nurses in India’s half a million villages to perform life-saving procedures and ultimately, women won the right to free healthcare during pregnancy.<sup>4</sup>

Community organisations, even those without health programming experience, can be effective in serving the health needs of their communities. For example in Egypt, community health workers were successfully trained to influence decision-making around maternal and child illness. In this quasi-experimental design, women’s knowledge and behaviours increased along with some care-seeking behaviour.<sup>5</sup> In the US and the UK, patient advocates have actively participated

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in and influenced professional standards-setting activities such as NICE<sup>6</sup> and ACOG<sup>7</sup> guidelines for the management of hypertension in pregnancy. The objective is to highlight for the public important topics in maternal health, and if litigation is successful, hold governments accountable and use this success to fuel further advocacy efforts.<sup>8</sup> This has been most commonly applied in the sphere of family planning.<sup>9</sup>

## Pre-eclampsia advocacy

Globally, pre-eclampsia and the other hypertensive disorders of pregnancy are leading causes of maternal and infant illness and death. In a recent WHO systematic analysis, hypertension was the second most common direct cause of maternal mortality worldwide (14%).<sup>10,11</sup> Many of these deaths are linked to substandard care. These devastating statistics reflect the tremendous need for increased funding, quality improvement, and research related to these life-threatening disorders. As a spectrum disorder, pre-eclampsia impacts women differently and its impact may be underestimated.

Policymakers expect to hear from their constituents. As such, politicians have processes in place and staff who are dedicated to responding to input and requests from the public. At an individual level, pre-eclampsia advocates must engage regularly in proactive and co-ordinated advocacy to drive government policies and programs so that they are in line with their concerns. Fortunately, doing so is easy and inexpensive; one need only have a few tools, such as a smart phone (or even landline) or computer, and some basic contact information in order to be an effective pre-eclampsia advocate.

The Preeclampsia Foundation has a broad advocacy approach. It is focussed on supporting efforts to reduce maternal and infant illness and death due to pre-eclampsia and the other hypertensive disorders of pregnancy. The objectives include providing patient support and education, raising public awareness, increasing research investment, and improving healthcare practices and quality. As such, the Preeclampsia Foundation not only provides opportunities for its supporters to write, call, and otherwise urge elected officials to support policies, programs, and investments to advance pregnancy hypertension care improvement but also supports the communities' involvement in achieving these goals. It does this by providing on-line advocacy resources (<http://www.preeclampsia.org/advocacy/materials-for-advocates>), fund-raising, and engaging in policy advocacy and communicating with elected officials directly.

## Advocacy to action

Through the work of the Preeclampsia Foundation and the voices of hundreds of women and families affected by pre-eclampsia, in 2012, the U.S. Department of Health and Human Services designated 'May' as Preeclampsia Awareness Month on the U.S. National Health Observances Calendar. The month designation annually provides an opportunity to drive awareness and educate individuals and organisations about the effects of pre-eclampsia and the importance of prenatal and postpartum care and education. The national designation followed the Preeclampsia Foundation's launch of an online petition. In just one month, the 'Hear Us Now' petition received more than 3000 signatures. Members of Congress were convinced to voice their support for the designation, and a formal request for national designation was made by Congress to the U.S. Assistant Secretary for Health.

The Preeclampsia Foundation has been keen to identify specific issues with which to assist and has been consistently embedded in the work of the research community in pregnancy hypertension. For example, the Foundation has been active in identifying the challenges toward the approval of new biomarkers for pre-eclampsia screening and diagnosis and develops solutions. The Preeclampsia Foundation has likewise worked in collaboration with organisations like the

American Congress of Obstetricians and Gynecologists and Society for Maternal-Fetal Medicine to support the development of improved maternal mortality and morbidity review systems and action steps at the state level. This has included ensuring that state maternal mortality review committees have patient representatives. Such advocacy is highly relevant, especially as maternal mortality in the USA is on the rise and pre-eclampsia remains a leading cause.

## Going global

More than 99% of the women who die from pre-eclampsia and the other hypertensive disorders of pregnancy do so in under-resourced settings. To help build awareness of pre-eclampsia outside the USA, the Preeclampsia Foundation is partnering with other like-minded global advocacy and professional organisations from Australia, Brazil, Ireland, the Netherlands, and Norway to sponsor the first-ever World Preeclampsia Day during 22 May 2017.

## Challenges

A number of challenges for maternal health advocacy remain. First and foremost, the health of mothers and children must be recognised to be linked with the sociocultural context in which they live so that outcomes can be addressed.<sup>8</sup> In many low- and middle-income countries, financial and resource constraints mean that organisations are understaffed and lack the basic capacity to carry out important health promotion and healthcare activities. In well-resourced settings, advocacy organisations need to limit their commitments to a manageable number so that their work plans can be met. Outreach is required so that the benefit of advocacy organisations reaches beyond bigger cities and into rural communities. This can be achieved, at least in part, by effective partnerships and co-ordinated efforts, particularly with the education sector. Advocacy organisations must measure the impact of their work so that they can use their resources wisely.

## Future directions

Advocacy efforts should be contextualised and focused on local, regional, and national priorities, and engaging policymakers and state and federal agencies. Advocacy requires clearly articulated demands, with a strategic focus and compelling evidence that identifies goals for policy change and clear political and stakeholder mapping.<sup>1</sup> The emphasis of maternal health messaging should move from 'problem-narratives' to solution-centered strategies.<sup>8</sup> Through advocacy, we need to build a culture in which citizens feel entitled and enabled to demand their rights, and health systems and governments are held accountable. It is essential that the full spectrum of stakeholders participate in advocacy efforts, from pre-eclampsia survivors to their families and care providers. Recognized as a critical strategy, there is a growing emphasis on monitoring and evaluation of the impact of maternal health advocacy initiatives. Innovative methods can be learned from other health fields.<sup>11,12</sup> We must turn our attention farther into the future, and seek growing investment in the link between pre-eclampsia and long-term health risks. Advocacy is an ongoing process without a defined endpoint as knowledge evolves and progress is made.

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