



Pelvic Pain
Foundation
OF AUSTRALIA

Mission Statement

Mission Statement & Purpose

The purpose of the Pelvic Pain Foundation of Australia (Foundation) is to build a healthier and more productive community by improving the quality of life of people with pelvic pain and to minimize the suffering and burden of pelvic pain on individuals, their families and the community through awareness, education, funding, support, research and improving access to treatment and services.

Objectives

The objects of the Foundation are to:

1. educate, provide information, awareness, understanding and access to treatment for people with pelvic pain, their families, health care professionals and providers, and organisations who work on their behalf and the community generally;
2. provide educational programs and services to the community to promote public awareness and understanding of the burden of pelvic pain;
3. support, promote, resource and provide financial assistance to support groups for people with pelvic pain and their families;
4. improve community access to teams of multi-disciplinary health care professionals;
5. support, encourage and fund innovative research to further knowledge of pelvic pain including discovering improved methods for the diagnosis, treatment and control of pelvic pain;

6. provide opportunities for medical and scientific researchers including to promote and participate in higher degree research in association with a public university or universities;
7. promote and participate in the study and furtherance of knowledge of pelvic pain throughout the world;
8. collect, publish and disseminate data, information and knowledge relating to the objectives of the Foundation;
9. collaborate with the community including consumers, carers, not for profit organisations, health care professionals, employers, funders, governments and other stakeholders in Australia and the world to achieve the Foundation's objectives;
10. facilitate the provision of advocacy and support for people living with pelvic pain and their families;
11. raise funds from governments and through public and corporate donations to achieve or to give effect to any of the objectives of the Foundation;
12. give financial and other assistance to any health care, scientific or community bodies, associations and institutions or other charitable bodies, associations and institutions in Australia and the world in any way connected with the objectives of the Foundation;
13. raise funds from governments and through public and corporate donations to achieve or to give effect to any of the objectives of the Foundation;
14. collaborate with the community including consumers, carers, not for profit organisations, health care professionals, employers, funders, governments and other stakeholders in Australia and the world to achieve the Foundation's objectives;
15. provide financial and other assistance to any health care, scientific or community bodies, associations and institutions or other charitable bodies, associations and institutions in Australia and the world in any way connected with the objectives of the Foundation;



16. enter into partnerships and collaborations with others to achieve or to give effect to any of the objectives of the Foundation; and
17. to do all such things and carry out all such purposes as are incidental or ancillary to the Foundation's objectives.

Current priorities

1. To encourage quality research into pelvic pain conditions.
2. To raise awareness and understanding of pelvic pain in health professionals.
3. To provide support for people with pelvic pain.
4. Promote education programs about pelvic pain.

We will strive towards these priorities in the next five years by:

1. investigating what is required to conduct epidemiological research to establish prevalence and occurrence of pelvic pain;
2. providing resources and information about pelvic pain through forums and easily accessible website resources;
3. commencing the process of providing support groups and online resources from a range of health professionals to people with pelvic pain conditions; and
4. establishing a trial program for high school students at Glenunga High School by the end of 2015.

Impact Statement

Pelvic pain affects women and men of all ages throughout our community. It is particularly a problem for teenage girls. While you may not believe you know someone with pelvic pain, it is common. However sufferers of pelvic pain often keep their problems to themselves, so it seems less common than it is.

Around 1 in 4 women between the ages of 16 and 24 years have a long term pelvic condition^{i,ii}. It is estimated to cost Australia \$6 billion per year in direct costsⁱⁱⁱ. We don't

have information on how much pelvic pain costs Australia in reduced workplace attendance and productivity, but in the USA this is estimated to amount to \$550 million^{iv}.

It is estimated that between 4-8%, or approximately 1 in 12 Australian men, will exhibit pelvic pain in the absence of a diagnosed medical condition or infection at some stage of their lives^{vvivii}. This equates to approximately 500 000 men across Australia alone and over 150 million worldwide. Initially pelvic pain in men was referred to as chronic prostatitis (CP), which is a painful condition associated with the inflammation of the tissue of the male prostate gland. However it is now widely accepted that many pelvic conditions, and not just prostate related issues, can lead to pelvic pain in men. Moreover, some men experience pain without the presence of a diagnosed medical condition, which is known as chronic pelvic pain syndrome [CPPS]. Pelvic pain in males can have different features to pelvic pain in women. For instance, onset in men is generally between 30 to 50 years of age, whereas in women it most commonly emerges in adolescence. Overall, persistent pelvic pain in both men and women has a significant impact in the lives of sufferers and requires further empirical investigation.

Persistent pelvic pain is also associated with great personal expense and limitation. For instance, people with pelvic pain have higher levels of depression, anxiety, stress and physical illness than others, even higher than people with other long term pain conditions^{i, ii, viii, ix, x}. People with one chronic pain condition, such as persistent pelvic pain, are also at increased risk of developing other chronic pain conditions. Despite this, there is limited support and health services available to people with the condition. Research with the potential to improve understanding and awareness of pelvic pain conditions is also limitedⁱⁱⁱ.

Whether you look at the human suffering or how much it costs – pelvic pain is a big problem throughout Australia and certainly the world.

ⁱ Pitts, M .K., Feerris, J. A., Smith, J M., Richters, J. (2008). Prevalence and correlates of three types of pelvic pain in a nationally representative sample of Australian women. *Medical Journal Australia*, 189(3), 138-143.

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- ⁱⁱⁱ The Pelvic Pain Steering Committee. (2011). The \$6 billion dollar woman and the \$600 million dollar girl: The pelvic pain report. Retrieved online January 12, 2014, from http://www.fpm.anzca.edu.au/Pelvic_Pain_Report_RFS.pdf
- ^{iv} Howard, F. M. (2003). Chronic pelvic pain. *Obstetrics & Gynaecology*, 101(3), 594-611.
- ^v Daniels, N. A., Link, C. L., Barry, M. J., & McKinlay, J. B. (2007). Association between past urinary tract infections and current symptoms suggestive of Chronic Prostatitis/Chronic Pelvic Pain Syndrome. *Journal of the National Medical Association*. 99(5), 509-516.
- ^{vi} Ferris, J. A., Pitts, M. K., Richters, J., Simpson, J. M., Shelley, J. M., & Smith, A. M. (2010). National prevalence of urological pain and prostatitis-like symptoms in Australian men using the National Institute of Health's Chronic Prostatitis Symptoms Index. *BJU International*, 105(3), 373-379.
- ^{vii} Strauss, A. C., & Dimitracov, J. D. (2010). New treatment for Chronic Prostatitis/Chronic Pelvic Pain Syndrome. National Institute of health, *Nature Reviews Urology*, 7(3), 127-135.
- ^{viii} Bair, M. J., Robinson, R. L., Katon, W., & Kroenke, K. (2003). Depression and pain comorbidity: A literature review. *Archives of Internal Medicine*, 163(20), 2433-45.
- ^{ix} Grace V., & Zondervan, K. (2006). Chronic pelvic pain in women in New Zealand: Comparative well-being, comorbidity, and impact on work and other activities. *Health Care for Women International*, 27, 585-599.
- ^x Anderson, R. U., Orenberg, E. K., Chan, C. A., Morey, A., & Flores, V. (2008). Psychometric profiles and Hypothalamic-Pituitary-Adrenal Axis Function in Men With Chronic Prostatitis/Chronic Pelvic Pain Syndrome. *The Journal of Urology*, 179(3), 956-960.