

## CASE STUDY

# WORKING TOGETHER TO SOLVE THE MYSTERIES OF POLYCYSTIC OVARIAN SYNDROME

In 2009, Professor Helen Teede of the Jean Hailes Foundation for Women's Health, and Professor Rob Norman, Director of the Robinson Institute led an Australian initiative to form a national alliance on Polycystic Ovarian Syndrome (PCOS) and successfully secured considerable government funding to support this initiative over the next three years.

The initiative brings together multidisciplinary clinicians, women with PCOS, researchers and government. The National PCOS Alliance is designed to provide a single voice for Polycystic Ovarian Syndrome and has agreed on a vision to improve the lives of Australian women with PCOS through education, research and evidence based health care.

The initiative worked closely with the Minister for Health and Ageing, Nicola Roxon, and the Australian Government committing to \$1,134,000 over three years to fund the National PCOS Alliance, specifically for the development of national evidence-based guidelines in PCOS and to support education and translation for consumers and health care professionals.

PCOS is a debilitating condition affecting 11% of Australian women of reproductive age and 21% of indigenous women. **PCOS is the most common cause of anovulatory infertility. Approximately a quarter of couples requiring IVF therapy have infertility complications related to PCOS.**

Once pregnant, PCOS places women at higher risk of pregnancy-related diabetes and pregnancy complications. Other important long-term implications include a four-seven fold increased risk of diabetes, increased cardiovascular risk factors and increased cardiovascular disease.

Australian research shows that 89% of women with PCOS saw more than one health professional before their diagnosis was made, 49% took longer than six months to have a diagnosis confirmed and 41% were very dissatisfied with the manner in which they were informed of their diagnosis.

The first task for the National PCOS Alliance is the development of the first national, and in many areas, international evidence-based guidelines for diagnosis and care of women with PCOS.



89%



Percentage of women who required multiple visits to a doctor before a positive PCOS diagnosis was made.

49%



Percentage of women who took longer than six months to have their PCOS diagnosis confirmed.

41%



Percentage of women who were very dissatisfied with the manner in which they were informed of their PCOS diagnosis.