

Media Release

Embargoed: March 15, 2010

Rheumatoid Arthritis champions refuse to let their disease get the better of them

As part of Arthritis Awareness Week, Arthritis Australia and the Australian Rheumatology Association are beginning a campaign today to give a voice to the almost 300,000 Australian women with rheumatoid arthritis.

The campaign is to be launched at Parliament House, Canberra and has the support of 12 female Federal MPs, including the Hon Julia Gillard MP, the Hon Julie Bishop MP, Senator the Hon Penny Wong, the Hon Jenny Macklin MP, the Hon Tanya Plibersek MP, the Hon Justine Elliot MP, the Hon Kate Ellis MP, Senator Carol Brown, the Hon Bronwyn Bishop MP, Senator Sue Boyce, Senator Rachel Siewert, and Mrs Kay Hull MP.

Rheumatoid arthritis (RA) is the most serious form of arthritis. It is not a rare disease, affecting around half a million Australians. Of these cases almost 60% are women.

The *Women's Insights into Rheumatoid Arthritis* book features the stories of 12 inspiring Australian women with this condition —as shared with their local female Federal MP.

The limited edition book was produced to increase support from the community, healthcare professionals and government for greater understanding and better management of rheumatoid arthritis. It has been supported by healthcare company Abbott with an unrestricted grant.

Ita Buttrose, Vice President Emeritus of Arthritis Australia, said today that creating the book was a powerful, emotional experience for all involved.

"It has been difficult for our RA champions – for that's what they are – to think back over the progression of their disease from when they were first diagnosed, through the years of endless pain and the many ways in which RA has changed their lives," Ms Buttrose said.

"I defy anyone not to be moved by their courage and their incredible optimism."

The campaign seeks to educate all Australians on the prevalence of the condition in young and middle-aged women in particular, and the significant impact it has on their lives.

"RA is a debilitating and extremely painful disease," Ms Ainslie Cahill, CEO of Arthritis Australia, said.

"Some of the women who have told their stories have not had a pain-free day since being diagnosed. Women's Insights is an attempt to raise the voice of RA and make it heard.

"Through the untold stories of 12 gutsy women, we're hoping to increase general understanding of the disease in the belief that better knowledge will help reduce the effects of RA in Australia and ultimately limit the impact on future generations."

It is hoped that the book provides inspiration for others affected by rheumatoid arthritis to get a proper diagnosis early on, to take control of their health, and to be more open with their family, colleagues and friends so they can help generate greater understanding and support of the condition. The book also aims to help healthcare professionals, as well as policy makers, realise that more needs to be done to provide better care and access to services and treatment.

“We know irreversible joint damage occurs in the first two years of RA and that earlier and more aggressive therapy can prevent or slow down its devastating effects,” said Dr Mona Marabani, President of Arthritis Australia.

“But still many people don’t understand the urgency of this situation, believing arthritis is all one disease, shrugging it off as an old people’s problem, and thinking nothing can be done.

“Women’s Insights sets out to change these misconceptions. RA is a serious condition. It can shorten life. It attacks people in their prime – often from 25 to 54 years of age – and affects more women than men.”

Ms Ainslie Cahill added that rheumatoid arthritis has a huge impact on the individual person both socially and financially. Many people miss out on the available services and treatments because they simply cannot afford them.

The 12 Australian women who stepped forward to break the silence for the ***Women’s Insights into Rheumatoid Arthritis*** book are:

- Renee Lang, aged 21, Adelaide, SA as told to the Minister for Early Childhood Education, Childcare and Youth and Minister for Sport, The Hon Kate Ellis MP, Member for Adelaide, SA
- Rebecca Henderson, aged 30, Griffith, NSW as told to the Nationals Chief Whip, Kay Hull MP, Member for Riverina, NSW
- Hayley Foyster, aged 33, Kingscliff, Queensland as told to the Minister for Ageing, The Hon Justine Elliot MP, Member for Richmond, NSW
- Suzie May, aged 35, Perth, WA as told to the Deputy Leader of the Opposition and Shadow Minister for Foreign Affairs, The Hon Julie Bishop MP, Member for Curtin, WA
- Amanda Glynn, aged 39, Perth, WA as told to the Australian Greens Whip, Senator Rachel Siewert, Senator for WA
- Despina Gonis, aged 48, Adelaide, SA as told to the Minister for Climate Change and Water, Senator the Hon Penny Wong, Senator for SA
- Christine O’Brien, aged 49, Melbourne, Victoria as told to the Minister for Families, Housing, Community Services and Indigenous Affairs, The Hon Jenny Macklin MP, Member for Heidelberg, Victoria
- Sabine Gunton, aged 54, Sydney, NSW as told to the Shadow Minister for Seniors, The Hon Bronwyn Bishop MP, Member for Mackellar, NSW
- Ann Goody, aged 56, Cooktown, Queensland as told to Senator Sue Boyce, Senator for Queensland
- Elleke Penny, aged 59, Melbourne, Victoria as told to the Deputy Prime Minister, Minister for Employment and Workplace Relations, Minister for Education and Minister for Social Inclusion, The Hon Julia Gillard MP, Member for Lalor, Victoria
- Judith Nguyen, aged 63, Sydney, NSW as told to the Minister for Housing and Minister for the Status of Women, The Hon Tanya Plibersek MP, Member for Sydney, NSW
- Barbara Dutton, aged 74, Burnie, Tasmania as told to Senator Carol Brown, Senator for Tasmania.

The book will be distributed to rheumatologists as an educational tool for their RA patients and can be downloaded from the Arthritis Australia website www.arthritisaustralia.com.au. Further copies will be distributed to all public/municipal libraries across Australia.

What these women want you to know:

RA does not discriminate:

- “I’m only 21 and while marriage and children are a long way off, what scares me is having to go off medication during pregnancy. Even in remission, that would terrify me. Then there’s caring for the baby. What happens if you can’t walk or are in the middle of a flare?” *Renee Lang*

RA is a serious disease:

- “My joints weren’t disfigured. I didn’t look like a sick person and I know some people dismissed me as a hypochondriac because there was no physical sign there was anything wrong.” *Ann Goody*

The impact RA has on the individual and their life:

- “With RA no matter how excruciating the pain, you learn to live with it. It’s the fatigue that knocks you rotten. You can have a beautiful night’s sleep and wake up feeling like you’ve been hit by a bus. I’d be so tired some days that I’d come home from work, look at the breakfast dishes and just want to cry.” *Amanda Glynn*

The importance of early diagnosis and your rheumatologist:

- “Doctors and pediatricians put it down to growing pains. But it was much more than that. When I walked my knees seriously hurt and often they’d lock so I couldn’t move at all. It was also agony to go down steps. My knees couldn’t deal with the downward pressure. Even if it was just stepping down off a kerb, my knees would give way under me and I’d end up in the gutter.” *Hayley Foyster*
- “The biggest mistake I made with my rheumatologist was not being honest. Like many women, I believed in a stiff upper lip. When my doctor asked how I was, I wouldn’t let on I’d been in such agony, even though I’d virtually crawled from my car to her office. Instead I pretended the pain wasn’t so bad. I didn’t want her to think I was a complainer.” *Sabine Gunton*

References:

1. Arthritis Australia 2008. Rheumatoid Arthritis.
http://www.arthritisaustralia.com.au/images/stories/documents/info_sheets/english/colour/Rheumatoid%20Arthritis.pdf
(Accessed on 14 January 2009)
2. Access Economics Report, Painful Realities: The economic impact of arthritis in Australia in 2007
http://www.arthritisaustralia.com.au/images/stories/documents/reports/Painful%20Realities_report_Arthritis%20Australia%20and%20Access%20Economics_070731.pdf

-ends-

Issued on behalf of Arthritis Australia by Hill & Knowlton

For further information please contact:

**Vanefsha Crook, Hill & Knowlton
02 9286 1251, 0412 448 536**

Or

**Rory O’Connor, Hill & Knowlton
02 9286 1283, 0419 628 905**