



Australia's
National
Infertility
Network

LTD
ACN 061 639 549

annual report 2001

“ . . . after reading the personal story, I had a warm feeling, knowing that I was not the only one who had gone through the great sadness and loneliness of infertility. All my life I wanted children so badly, and being a nurse, I thought that one day it would be my turn. I turn 60 in February and now find myself very much alone, as all my girlfriends and family are seeing their children marry and are experiencing extreme joy as the grandchildren arrive. I feel alone again and not able to relate to them. I feel like I’m standing on the sidewalk watching the parade go by. It is good to know that ACCESS is a support group for people just like me and I would really appreciate your help. . . .”

(Enquiry letter received October 2001)

2001 Objectives

Throughout 2001, ACCESS has worked to develop support services and to represent consumer interests. This has been achieved through representations to state and federal governments, international medical organisations and public policy bodies. In responding to the needs of infertile people in a challenging world, ACCESS has been committed to implementing strategies to achieve our support, education and advocacy objectives. The continuing support of our *corporate benefactors*, and our *Patrons*, Glynis Nunn-Cearns OAM and Hazel Hawke AM, has been crucial in providing the resources and public recognition to achieve our objectives.

.Highlights for 2001 have included:

Support

The ACCESS infertility OPTIONS Groups have catered for the diverse experiences of people who suffer from infertility. Groups have included:

- those considering donor gametes or who have children conceived in this way;
- those who have suffered an IVF Miscarriage;
- those who are approaching life without children after many years of treatment and
- “men only” as a way for men to speak with other men about their infertility experience.

Infertility fact sheets have been our most requested resource from individuals and clinics. Additional titles to the existing range of 36 will be introduced in the new year.

The ACCESS national newsletter has provided support with medical and scientific advances, peer support and personal stories to 4,800 individual subscribers. The newsletter was also distributed to Australia and New Zealand infertility clinic directors, nurse co-ordinators, counsellors, international consumer associations, clinicians and scientific bodies, Health Ministers, selected politicians, media, Family Planning and Community Health clinics.

The Infertility Counsellors’ Network has provided valuable support for those who would like to discuss infertility issues with a professional who understands infertility.

The Member Contact Network has been promoted through the national newsletter.

Informal peer support has continued to be provided through the office, supporting directors, governors and volunteers.

Education and Networking

Presentations focussing on our national and international work to support infertile people have been made possible with generous corporate support from Serono and Organon. Presentations included the following:

- World Health Organisation meeting on the *Medical, Social & Ethical Aspects of ART*, Geneva. Planning committee and speaker on *Consumer perspectives on ART*. A report will be published in 2002.
- International Consumer Support for Infertility (iCSI), symposium was organised by ACCESS in co-operation with sister associations, Wunschkind, Germany; Electronic Infertility Network (EIN), United Kingdom and the American Infertility Association (AIA). Patient leaders from 19 countries participated.

- In addition, two fact sheets were co-written and produced by ACCESS and iCSI in English, French and German titled: *Building your family with the help of ART – how can we share this with our child?* and *Infertility: a fact sheet for relatives and friends*.
- European Society of Human Reproduction and Embryology (ESHRE), Lausanne. Co-organised and participated in press conference, Celebrating Life: speaking with children about their conception with Professor Robert Edwards MBE as guest speaker, with families from Switzerland, United Kingdom and the United States.
- Nineteenth Annual Meeting of the Japan Society of Fertilization and Implantation, Yokohama. Lecture on *Current Practice on ART in Australia, as a patients’ Group*.
- A meeting with international patient groups, Kidsless Party and FINNRAGE was held in Tokyo, to share cultural and social perspectives with a view to establishing long term contact.
- International Federation of Fertility Societies (IFFS) meeting, Melbourne. Chairing two sessions, poster judge, exhibition booth.

Other national education and networking opportunities for consumer directors and governors have included:

- Invited speaker on the *Importance of customer service* at presentation of ISO 9901 certification to Repromed, Adelaide.
- Discussed ethical and consumer issues with members of South Australian Council on Reproductive Technology.
- Participated on panel on *Ethical Issues in Human Fertility* for post graduate medical students at the Dept. Psychological Medicine at Sydney University.
- Maintaining contact with federal and state health ministers and their departments in relation to issues which may impact on infertile people.
- Presented *Consumer issues in Reproductive Health Sciences* to Master of Medicine students at Sydney University.
- Meeting with clinic, nursing and counselling staff of Flinders and Repromed, Adelaide to report on ACCESS and discuss consumer issues.
- Regional Chapters and support groups have continued to be a valuable referral for people seeking contact in their home region. Spoke at meetings of the ACCESS Support Group (Wollongong, NSW), OASIS (Adelaide, SA) Friends of QFG (Brisbane, Qld) and DESTINY (Kogarah, NSW).
- Invited speaker, on *Understanding infertility, accessing information and donor issues* at the launch of information leaflets for the South Australian Council on Reproductive Technology
- Visited nursing and scientific staff at Queensland Fertility Group and IVF Queensland Sunshine Coast (Qld).
- Media interviews (more than 100) have included television, radio, newspapers and magazines in Australia and Europe.
- The ACCESS website has provided information about accessing fact sheets, newsletters and has ‘links’ to Australian and international infertility sites.

Professional partnerships

ACCESS has been represented on several organisations and committees to bring consumer perspectives to the process:

- The ACCESS consumer representative on the *Reproductive Technology Accreditation Committee (RTAC)* in 2001 has been Dr Linda Fiske. With increasing numbers of clinics to inspect, Linda has been ably supported by ACCESS Governors, Doreen Burge and Jenny Walsh who have acted as alternates. ACCESS values the expertise and commitment they have brought to this important aspect of our work. Additional alternates have been identified to join the team in 2002.
- ACCESS has been represented on the IVF Directors' Group, a sub-committee of the Fertility Society of Australia (FSA) and on their governing body, the FSA Federal Council.
- The AIHW Reproductive Health Advisory Committee: in cooperation with the Department of Health and Aged Care, to support the AIHW National Perinatal Statistics Unit (NPSU) in the preparation of a reproductive health report which is accessible to consumers and health professionals.
- Clinical Trials Network, an association of clinical and scientific members of the Fertility Society of Australia (FSA), collaborating to improve reproductive health and treatment by participating in randomised clinical trials and encouraging knowledge and utilisation of information gained from such trials.
- Andrology Australia Consumer Advisory Group. Its purpose has been to provide Andrology Australia with a consumer perspective on a community education program to identify the needs of the community in relation to the key reproductive health issues for males.
- ACCESS has responded to the Australian Health Ethics Committee (AHEC) NHMRC review of the national ethical guidelines for ART.
- ACCESS has been partnering the Health Media Group to develop and launch the *myfertility* site.
- ACCESS has maintained contact and discussion with providers, government and public policy bodies through membership of the European Society of Human Reproduction and Embryology (ESHRE).
- The Patient's Network (TPN) editorial board. TPN is a newsletter appearing three times a year, under the auspices of the International Alliance of Patients Associations (IAPO).
- ACCESS has been a voice in national consumer health issues as a 'voting member' of the Consumers' Health Forum.
- ACCESS has participated in national discussion on the role of the law and ethics in health care with medical practitioners, academics, lawyers, philosophers and consumers through membership of the Australian Institute of Health, Law and Ethics.

Infertility is a major life crisis affecting all areas of a person's life. People need help to move through this crisis. ACCESS provides support, information and advocacy for infertile people.

Future directions

- The ACCESS website will be expanded to incorporate on line access of the newsletter to the current issue for members and selected past issues available for the public. Support will be sought to build services on our website as demand for information on the internet increases.
- The range of infertility fact sheets will be extended to include topics: *How to choose an IVF clinic and understand success rates, Your religious beliefs and IVF and Dealing with success: a guide for support groups.*
- The 3rd International Consumer Support for Infertility (iCSi) meeting of patient leaders will be held in Vienna.
- World Infertility Month (WIM). ACCESS and iCSi will celebrate WIM with special events. iCSi is partnering the American Infertility Association, who initiated WIM.
- The possibility of providing telephone counselling by professional infertility counsellors will be explored as will the feasibility of conducting a national donor drive to raise awareness of the need for altruistic donors to assist infertile people.
- ACCESS will actively strengthen our established partnerships with infertility support groups worldwide including the Asia Pacific region, Europe and the USA to raise global awareness of our collective needs and to challenge the cultural taboos surrounding the experience of infertility.
- The 2nd Bertarelli Foundation Global Conference to be held in Prague. Planning committee and speaker.
- An internet service company is negotiating the use of ACCESS fact sheets on a popular site.

The dedication and commitment of the Chair, Jenny Billington and Vice Chair Debbie Jeffrey, Directors, Governors and staff to achieving our objectives in 2001, has been greatly appreciated.

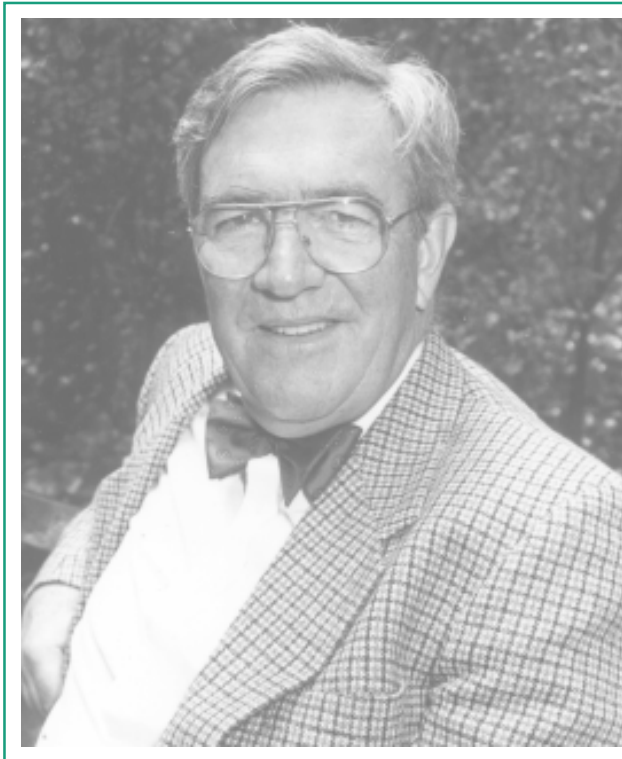
Sandra K. Dill AM
Executive Director



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Vale Ian Johnston AM

(16th February 1930 to 19th March, 2001)



Ian Johnston AM was a founding Governor of ACCESS. He was the Retired Chair of Melbourne IVF and retired Head of the Reproductive Biology Unit at the Royal Women's Hospital in Melbourne. The Royal Women's was the second hospital in the world to succeed with IVF by delivering the world's third IVF baby. Ian was also the Founding President of the Fertility Society of Australia and a Senior gynaecologist at the Royal Women's Hospital where he practiced in reproductive and menopausal medicine. He was respected internationally and was affectionately known as the Father of IVF in Australia. Many clinicians in Australia did some of their infertility training under his supervision.

Ian Johnston supported consumer involvement in ART regulation and policy development from its inception in the mid 1980s and he was always generous with his time and advice. He supported consumer participation on the Council of the Fertility Society of Australia and at international scientific and consumer forums.

Ian was involved with ACCESS from the outset and we were proud to have him on our Board of Governors. We will miss his counsel and we will remember him with affection, for his personal support and especially for helping thousands of infertile couples to have a family.

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