

Consumers' Health Forum
of Australia

Annual Report

2001/2002

Consumers' Health Forum of Australia

The Consumers' Health Forum of Australia Inc, established in 1987, is Australia's leading non-government organisation representing consumers on health care issues. CHF establishes policy in consultation with its members, more than 100 health consumer organisations. It provides a balance to the views of government, industry, service providers and health professionals.

The vision of CHF is to see consumers shaping health policy and health delivery systems in Australia. Our mission is to provide a respected and informed national voice for health consumers. CHF works collaboratively with other health consumer organisations providing a leadership role in representing the views of consumers at a national level.

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Chairperson's Report

Welcome to the Annual Report of the Consumers' Health Forum of Australia (CHF). The Annual Report gives us a chance to reflect on what we have achieved throughout the year. It is also a chance to report to you, our members and strategic partners, not only about the way we have managed the organisation's finances, but how we have been able to advocate, inform and shape policy on your behalf.

I feel quite nostalgic writing this report as it is one of my last official duties as a member of CHF's Governing Committee. My term as Chairperson finishes in October 2002 and I have decided not to stand for the next Governing Committee. I have been on the Governing Committee for eight years and have seen many changes in the organisation over that time. I think that I am leaving the organisation in good shape and I am very proud of what we have achieved.

In providing a voice for health consumers at a national level, we have tried in the past 12 months to focus on some core issues. It can be really easy to get caught up in the myriad of change process going on in health and to forget to look at the system as a whole. Our booklet *Getting the Basics Right* tried to spell out in simple terms what we expect from the system – more coordination, less fragmentation, better information for consumers, more respect for individuals and families and less additional payments for people who do not have the ability to pay. Simple messages, but they seem difficult to convey at times.

These are exciting yet difficult times for consumer participation in health. On the one hand, there is an increased interest in participation at all levels, yet on the other, the financial resources available to the consumer sector remain frustratingly difficult to find. We have, however, been able to mobilise an impressive range of other resources — our time, our skills, our

humour and our experience as health consumers — and we continue to bring these resources to the partnerships we are involved in.

We have consumer representatives on more than 200 committees and boards, all working to make sure that the voice of health consumers is heard. This is an amazing effort and I would like to pay tribute to all those health consumers who give up their time to take on this work. I know that it is not always easy. I know that many of you feel frustrated that you have to repeat the same points over and over again. Don't give up, we are making a difference!

We still don't have funded health consumer organisations in each State and Territory, even though the bulk of health services are delivered at that level and there is a key role for consumer organisations to play in accountability. The decision not to support the emergence of the Health Consumers' Network of NSW was particularly disappointing in this area. Governments will need to be more courageous if health consumers are to have an effective voice at State level.

Within health consumer organisations we have been facing some core challenges. Some argue that our reliance on government funding prevents us from criticising government policy. Others are nervous about us accepting funding from private sources, particularly the pharmaceutical industry, in case we are used by them to promote their agenda.

For me, the question has been: 'How do we get the resources we need to be able to communicate with our members and provide a national voice?' I have encouraged the organisation to stay 'at the table', to work in partnership and to bring its concerns to government and to the health system. But even I get frustrated at times that our contribution is not respected enough and that we seem to have to

struggle harder and harder for the resources we need to provide a strong and effective national voice for health consumers. With our record of cooperation and constructive engagement, I call on the government and the Department of Health and Ageing to examine and work with us to solve this problem of insufficient core resources.

At some tables we have made real progress and we should be proud of these achievements. In developing the *Statement for Consumer and Community Participation in Health and Medical Research* we worked with researchers to find common ground. The vision of consumers and researchers working in partnerships based on understanding, respect and shared commitment to research will improve the health of humankind. The co-endorsement of the *Statement on Participation* by the National Health and Medical Research Council and CHF is an achievement for us all.

The review of CHF's consumer representatives program in 2001/2002 has also opened up the opportunity for better dialogue with the Department of Health and Ageing about the contribution our consumer representatives make to health policy development. The resulting workshop for all of our consumer representatives, the first to be held in many years, was a welcome refresher for all who were able to attend.

In closing, I would like to pay tribute to the many people I have worked with at CHF over the last 9 years. I particularly want to acknowledge the three Executive Directors who I have worked with - Kate Moore, Matthew Blackmore and Helen Hopkins - each of whom have made their own exceptional contribution to the organisation. I want to thank the many current and past staff members who have done amazing things with scant resources. I also want to acknowledge the many people in CHF's member organisations

who serve on the Governing Committee, represent us on other boards and committees and who help us shape our views and approaches. I have had a wonderful time working with all of you and I am inspired by your commitment, humour and skills. I am confident that CHF is in a position to grow and to shine!

Lou McCallum
Chairperson

What We Do

Aims

The aims of the Forum as stated in its Constitution are:

- (i) to provide a means of optimising the participation of consumer and community groups in national policy, planning and service decisions which affect the health of consumers
- (ii) to promote a public and preventive health approach which recognises the health impact of other government policy areas
- (iii) to promote a just and equitable distribution of resources to redress inequalities in the health status of different groups of the Australian population, noting the pluralistic nature of our society
- (iv) to encourage the development of health services which are:
 - (a) effective in enhancing the capacity of people to participate as fully as possible in community life
 - (b) responsive to consumer needs and preferences
 - (c) community based and managed
 - (d) respectful of human rights
 - (e) culturally relevant
 - (f) universally accessible
 - (g) cost effective
- (v) to promote the rights of all consumers to be involved in health policy, planning and service decisions.

Objectives

The objectives of the Forum are:

- (i) to develop and promote an understanding of consumer experiences and views and identify priorities and goals by consulting consumer and community groups

- (ii) to facilitate the development of and enhance the capacity of consumer and community groups (particularly those currently disempowered) to participate in national issues which affect their constituencies by:
 - (a) providing information and advice on health issues, policies and decision making processes
 - (b) facilitating stronger relationships, cooperation and coordination between the groups
 - (c) facilitating closer links and more open communication between these groups, the Federal Government and relevant Federal Government departments
 - (d) convening workshops and seminars and providing an appropriate interface between consumers and experts
- (iii) to raise and represent consumer views and, in particular, advise the Commonwealth Minister for Health and Ageing and the Department of Health and Ageing of these views
- (iv) to monitor the opportunities and processes for consumer participation and to work with the Commonwealth Department of Health and Ageing to assist it to become more open, accountable and responsive to consumers
- (v) to monitor and analyse national health policy development, planning, resource allocation processes and outcomes
- (vi) to facilitate, and in some instances, fund research and conduct education projects on matters affecting consumers
- (vii) to advocate, publicly, measures which will contribute to achieving the Forum's aims and objectives.

Strategic Plan

The Forum's current Strategic Plan focuses on three themes or work areas:

- Health policy, practice and outcomes
- National voice
- Governance and management

Key Work Area 1: Health policy, practice and outcomes

Aim: To contribute towards the improvement of peoples' health and well-being

- Objective 1: Ensure accessibility to a high quality and responsive public health system, and to high quality outcomes through public and private health care
- Objective 2: Strengthen the ability of consumers to participate in and strategically influence health policy, planning and service delivery
- Objective 3: Address inequities in health outcomes for particular groups
- Objective 4: Improve information from the health system to health consumers to use in their decision making and problem solving about their health

Key Work Area 2: National voice

Aim: To represent the views and interests of health consumers at a national level

- Objective 1: Strengthen relationships with consumer organisations.
- Objective 2: Provide advice to government in a constructive and timely manner
- Objective 3: Establish, promote and maintain a range of strategic alliances with other organisations to further the aims of CHF
- Objective 4: Promote the views and interests of health consumers through the media, publications and other channels

Key Work Area 3: Governance and management

Aim: To support the work of the Forum through effective governance and management

- Objective 1: To strengthen CHF's governance and management structures and processes
- Objective 2: To enhance the effectiveness of CHF's Secretariat
- Objective 3: To optimise the use of funds available to CHF

Submissions and reports

CHF completed the following main submissions and reports during the year. Most are available to download from our website www.chf.org.au.

- Comment to the Office of the Federal Privacy Commissioner on the Draft Health Privacy Guidelines, July 2001
- Submission to the Department of Health and Ageing on the Draft Legislation for the Better Medication Management System, July 2001
- Developing a Statement on Consumer and Community Participation in Health and Medical Research, Final Report, August 2001
- Input Performance Indicators for the Prescription Medicines Program for the Therapeutic Goods Administration (TGA), advice based on previous written submissions, October 2001
- 'Getting the basics right: Health policy proposals for the next Commonwealth Government', Election brochure, October 2001
- Consumer awareness and education strategy: Standards for *Pharmacist Only* and *Pharmacy Medicines*, January 2002
- 'What do consumers expect from HealthInsite?' Final Report to the Department of Health and Ageing, May 2002
- Discussion paper for CHF's members on the pilot project to provide consumer input to the Australian Drug Evaluation Committee (ADEC), May 2002
- Comment to the Department of Health and Ageing Interdepartmental Committee Review of the regulatory framework for private health insurance, May 2002
- Discussion paper for CHF's members on consumer representation on Medical Services Advisory Committee (MSAC) supporting committees, May 2002

- Comment to Australian Pharmaceutical Manufacturers Association (APMA) Code of Conduct Review, May 2002
- Cholesterol lowering medication project communication strategy, June 2002

CHF and the Department of Health and Ageing collaborated in the review of the CHF Consumer Representatives Program resulting in another key report for the year.

- 'Evaluation of the CHF Consumer Representatives Program' by Chalkley Consulting and Artcraft Research, May 2002.

Some CHF resources

Choosing your medicine – Making an informed decision about complementary and non-prescription therapies
ISBN: 1 876034 21 1, CHF Ref: 178, May 1999, 49 pp + Appendices, \$22.00

Easing the burden: The Pharmaceutical Benefits Scheme and people with chronic conditions
ISBN: 1 876034 20 3, CHF Ref: 180, March 1999, 51pp + Appendices, \$25.00

Understanding consumer behaviour and experiences in relation to the use of medicines: Literature Review
ISBN: 1 876034 24 6, CHF Ref: 232, July 1999, 64pp, \$25.00

Guidelines for consumer organisations receiving pharmaceutical industry funding for consumer education
ISBN: 1 876034 36 X, CHF Ref: 270, June 2000, 5pp, \$11.00

Submission to the external review of consumer outcomes of the Quality Use of Medicines (QUM) strategy in Australia
ISBN: 1 876034 36 X, CHF Ref: 264, October 2000, 17pp, \$15.00

Consumer Medicine Information – Ask for it!
ISBN: 1 876034 37 8, CHF Ref: 271, June 2000, 23pp + Appendices, \$15.00

Health information on the Internet

Consumers have a thirst for knowledge and are increasingly using the Internet as a source of information. However, the quality of health information on the Internet varies, ranging from evidence-based to misleading.

Earlier this year CHF prepared a report, 'What do consumers expect from HealthInsite', based on consumer consultations about their experiences of Internet health information. One of the issues covered was ways for people to assess the credibility of Internet health information.

Assessing credibility

The most frequently mentioned features of a good Internet site for health information mentioned were:

- ease of access and navigation, clear presentation;
- use of appropriate language;
- completeness of the information; and
- ways to assess the credibility of the information provided.

A good website provides information about itself and who is behind it, including authors' professional backgrounds and/or qualifications. It includes details about the source of the information contained, shows clearly when it was written and updated and includes current information.

Preferably, the site is connected with an organisation or individual with an existing good reputation in the real world - such as government regulators, professional colleges, universities and research institutes or known not-for-profit organisations.

Consumers questioned the value of references as a way to assess the credibility of information as it could be hard to know how much weight to attach to references and an apparently impressive reference list could be misleading.

Most people suggested other ways of cross-checking the information, such as links to other sites for the complete reference, or links to and from other known credible sites, or endorsement by a recognised authority.

HealthInsite

CHF's report focused, in particular, on consumers' expectations of HealthInsite, the Australian Government's Internet site for health information, set up by the Commonwealth Department of Health and Ageing. Its aim is to provide Australians with a place to find high quality and relevant health information. HealthInsite is a portal or gateway providing a search facility and links to websites or webpages that have been assessed by HealthInsite as meeting certain standards of quality.

Consumers strongly supported the focus of HealthInsite on providing quality health information for consumers. A government health information website should provide easy access to practical information about government-funded health services and benefits, including entitlements. Specific suggestions for forward planning included:

- promoting awareness about HealthInsite among consumers;
- adopting strategies to assist consumers to obtain information about health services and resources within different layers of government and the community, including self-help and consumer groups; and
- short, prominently located, plain English explanations of what HealthInsite accreditation meant about the sites accessed and the information they contain.

However, the establishment of an ongoing monitoring and review program, including diagnostic testing involving consumers, was seen as critical to ensure that the site is easily accessible, navigable and understandable. This was seen as especially important for first time users,

people with little Internet experience and people with lower education levels. It is a major limitation on the Internet's value to health consumers that those who are at greatest risk of poor health and most need high quality health information, are least likely to have access to it through the Internet. For example, 63% of retired people, 31% of people who are unemployed and 30% of low income people are projected to still be without Internet access at home in 2003¹.

In light of the report findings, and following feedback from CHF's workshop for consumer representatives, CHF hopes to re-design its website to provide improved ease of access and navigation, clear presentation and increased interactivity, with and between, members and consumer representatives.

¹ Lloyd R, Hellwig O (2000) Barriers to the take-up of new technology. Discussion Paper no. 53, NATSEM, Canberra.

Consumer input to Australia's evaluation process for medicines

A new CHF pilot project, funded by the Therapeutic Goods Administration (TGA), is giving Australian health consumers input to the approval process for prescription medicines for the first time.

CHF provides written submissions for consideration by the Australian Drug Evaluation Committee (ADEC) about how access to new prescription medicines may affect consumers. ADEC is an expert statutory committee of the TGA. The TGA evaluates scientific and medical research presented by pharmaceutical companies for new prescription medicines on the basis of safety and efficacy.

The information that CHF provides in a consumer submission to ADEC includes:

- consumers' quality of life issues such as side effects, pill burden and timing of doses;

- benefits and problems for consumers with current treatments for a particular illness;
- consumers' concerns about the benefits and risks of the new medicine;
- particular information consumers need about the new medicine; and
- public health implications.

How CHF consults with members on this project

CHF staff members involved in this project are bound by confidentiality agreements with the TGA. The TGA provides pharmaceutical manufacturers with an undertaking that commercial-in-confidence information will be kept secure. This means that CHF consultations with consumers are limited to small focus groups about general areas of drug treatment and obtaining information from the public domain.

CHF's member organisations assist by:

- informing CHF if they hear about new medicines for particular illnesses being approved in other countries, for example, through their links to consumer organisations overseas.
- advising CHF if their members are participating in clinical trials. This may suggest an application for marketing is near and collecting information for a consumer submission might be useful.
- advising CHF if their members are receiving medication that is not currently approved in Australia through special access schemes, the Internet or importing for their own use.
- indicating willingness to arrange small focus groups on general categories of medicines that may affect them.

The pilot project will be evaluated by CHF, the TGA, the ADEC and industry before the end of its 12 month timeframe.

Review of the consumer representatives program

CHF has been acknowledged as playing a key role in the development of consumer participation and representation in Australia over the past decade¹. One part of CHF's contribution has been to provide accountable consumer representatives from all over Australia and from a broad health interest base to a growing number of Department of Health and Ageing committees.

Representation on committees provides consumers with opportunities for input on many of the Department's most important decisions on health policy. The Consumer Representatives Program provided by CHF also assists the Department to consider consumers' issues and concerns during policy development and maintains a health policy focus on improving outcomes for consumers.

Consumer representatives in health face an extremely difficult task to provide up to date, considered, informed and accountable comment on numerous complex and technical topics. The support CHF has provided for consumer representatives has been a major strength of CHF's Consumer Representatives Program. CHF's representatives have been able to contribute to a national view of health issues, beyond a specific disease focus or their individual experience of health services and treatments, and to propose various strategies for obtaining wider consumer input to Departmental processes and activities.

The CHF Consumer Representatives Program has grown substantially and the number of health-related committees for which CHF is providing consumer representatives has increased from 30 to 93 representatives since 1990. These consumer representatives participate in approximately 200 health-related committees. A review of the effectiveness of the Consumer Representatives Program

was proposed by CHF as timely and was conducted by independent consultants during 2001 - 02, with funding and input from the Department of Health and Ageing².

Findings from the review

The review found the CHF Consumer Representatives Program was well respected and its aims and objectives were met appropriately, efficiently and effectively. The review also found that CHF was constrained in its ability to provide adequate training to CHF representatives. Opportunities for improvement in communication between CHF and its consumer representatives and CHF and Departmental committee secretariats were also identified. The increase in size of the task of managing the Program, which has not been matched by a growth in CHF resources, was considered to be one of the major difficulties. Other key difficulties were the inconsistent approach to consumer representation within the Department and the lack of adequate resources and training across the Department regarding consumer participation.

The Review Report identified key directions for improving the Program and made recommendations to both CHF and the Department of Health and Ageing for strategies to improve consumer representation. The recommendations fell into two main categories:

1. The need for a consistent approach to management and support of consumer representation by the Department of Health and Ageing – including the need for policies, protocols, training for Departmental staff providing the secretariat for committees with consumer representatives, and funding for CHF to manage the Consumer Representatives Program.
2. The role and tasks for CHF in managing and supporting the Consumer Representatives Program –

including recruitment of representatives, orientation, training, briefing and debriefing, communication, accountability, performance, and policy development.

Consumer representatives workshop

An early outcome of the Review was that CHF received funding from the Department of Health and Ageing for a workshop to work with its consumer representatives on a response to the review. The consumer representatives workshop, held on 27 - 28 June 2002, examined the recommendations of the Review Report, mapped the extent of the consumer representatives program across a wide range of national health issues and included brief policy updates in specific areas CHF has been working on recently. The facilitators provided a summary of the current trends in consumer participation from a theoretical perspective which was of interest to many participants.

Consumer representatives agreed that there are actions needed by all three stakeholders, the consumer representatives, CHF and the Department of Health and Ageing, to progress good practice in consumer representation. All three groups need to build their accountability and have requirements for resources that are crucial to an effective program. Funding for CHF to develop and conduct annual training meetings for consumer representatives and provide opportunities to bring sub-groups together for the purpose of coordinating policy input in the relevant areas and to identify emerging systemic issues is urgently needed.

An overall challenge for CHF is the need to continue and strengthen mechanisms for monitoring the connection between national health policy priorities for member consumer organisations, the work of the individual consumer representatives, and the strategic use of one of its key services, the Consumer Representatives Program. CHF has contributed to greatly improved consumer involvement in many

areas of health. Major challenges that remain are to:

- achieve a broader level of representation;
- improve the quality of representation; and
- achieve more effective involvement of consumers in improving the health system, and influencing health outcomes.

CHF recognises the value of the contributions its consumer representatives make to the health outcomes of the Australian community. Ensuring good practice in all levels of consumer representation and its management through the CHF Consumer Representatives Program and Departmental committee secretariats will encourage, protect and enhance the work.

The report on the response to the review of the CHF consumer representatives program will be available for circulation to CHF's members and consumer representatives in 2002/2003.

¹ NRCCPH (2002) *A Literature Review: Consumer participation in Primary health Care*, National Resource Centre for Consumer Participation in health, La Trobe University, Melbourne

² Chalkley Consulting with Artcraft Research (2002) *Evaluation of the Consumers' Health Forum Consumer Representatives Program*, available on request from the Consumers Health Forum of Australia, Canberra

Governance and Management

Legal status

The Consumers' Health Forum of Australia Incorporated is an association incorporated under the *Associations Incorporation Act 1991* (ACT).

Governing Committee

The Governing Committee is responsible for all facets of the Forum's management and meets face-to-face three times a year.

Voting members of the Forum elect a Governing Committee every two years at an Annual General Meeting (AGM). The next AGM will be held on 24 October 2002. The Constitution provides for a 12 member Governing Committee, comprising:

- five members from organisations that are constituted on a national basis
- seven members from organisations that are not constituted on a national basis.

The elected members of the Governing Committee in 2001-2002 were:

- Jenna Bateman (Mental Health Coordinating Council)
- Marg Brown – Treasurer until 11 June 2002 (Health Consumers of Rural and Remote Australia)
- Amanda Cornwall to 17 July 2001 then Sally Crossing (Health Consumers Network NSW)
- Peter Dhu (Australian Speak Easy Association)
- Margaretha Hanen (Federation of Ethnic Communities' Council of Australia)
- Lou McCallum – Chairperson (Australian Council of Social Service)
- Russell McGowan – Secretary (Health Care Consumers Association of the ACT)
- David Menadue (National Association of People Living with HIV/AIDS)

- Mitch Messer – Vice Chair (Health Consumers' Council of WA)
- Christopher Newell (Tasmanians with Disabilities)
- Sheila Rimmer (Council on the Ageing)

Jenna Bateman

Mental Health Co-ordinating Council

Jenna is the Executive Officer of the Mental Health Co-ordinating Council and has been involved in the mental health sector for 20 years. She has experience in acute care, research, and community-based/not-for-profit mental health services and has a strong commitment to service providers taking account of a person's community setting when planning care.

Her position and experience mean she is well acquainted with the issues arising from the interface between the health and community sectors, particularly as it affects people with a disability. She is keen to see the development of clear guidelines on how, and at what point, care is transferred to community-based services. Jenna is also a member of the NSW Mental Health Policy Implementation Group, the NSW Health NGO Advisory Group, the Quality Management Services NGO Reference Group and the Advisory Group for the implementation of the National Suicide Prevention Strategy in New South Wales.

Marg Brown – Treasurer (until 11 June 2002)
Health Consumers of Rural and Remote Australia

Marg is Chair of Health Consumers of Rural and Remote Australia (HCRRA), a national organisation that looks after the special health needs of people living in rural, remote and isolated areas. The organisation represents consumer views at the 'grass roots' and works in collaboration with health professionals and other

consumers/organisations and the Council of the National Rural Health Alliance.

Marg lives on a property at Kulkami in South Australia's Mallee. She represents rural and remote consumers on a number of committees:

- Adelaide University Outback Training Program Reference Group
- Convenor of the Consumer Standing Committee of the General Practice Partnership Advisory Council (GPAC)
- GPPAC Council member.
- Health Insurance Commission Consumer Advisory Committee
- Murray Mallee Division of General Practice Outcomes Based Funding Group
- Department of Rural Health, Flinders University

Amanda Cornwall (until 17 July 2001)
Health Consumers' Network (NSW)

Amanda has been a legal policy officer at the Public Interest Advocacy Centre (PIAC) since 1995. She was also Executive Officer for the NSW Cosmetic Surgery Inquiry in 1999. PIAC is an independent, non-profit legal and policy centre that strives to foster a fair, just and democratic society by empowering disadvantaged citizens, consumers and communities. PIAC has worked on health consumer rights issues since its inception in 1982. It was a founding member of CHF. The Centre's work emphasises effective public access to information and participation in society's governance.

With previous experience in government, the private sector and the community sector, Amanda is an effective advocate who has represented consumers on a number of committees and advisory groups on health, environment and social impact issues.

Sally Crossing (from 17 July 2001)
Health Consumers' Network (NSW)

Diagnosed and treated for breast cancer in 1995 when she was 49, Sally founded the Breast Cancer Action Group NSW in 1997. This group has more than 600 survivor members across the state and provides a voice for people affected by breast cancer who want to 'make a difference'. Sally is Co-chair of Cancer Voices NSW, a coalition of more than 100 cancer consumer groups, which acts on behalf of the 29,000 people diagnosed with cancer in NSW each year. She is also Deputy President of the Health Consumers Network NSW.

Sally sits on a number of boards, including The Cancer Council NSW, the NSW Health Participation Council and committees at both state and national levels. The NSW Minister for Fair Trading presented her with the inaugural Consumer Advocate Award in December 2001 for her work for women with breast cancer. Initially trained as an economist, and after a career in banking and government, she works full-time on a voluntary basis to represent health care consumers, particularly those who have experienced cancer.

Peter Dhu
Australian Speak Easy Association

Peter is the immediate past President of the Australian Speak Easy Association (ASEA), a self-help group for people who stutter. Peter held this position for five years and is currently President of the WA branch. He has been involved in ASEA since its establishment 22 years ago helping people who stutter through public awareness, advocacy, support and information.

As a spokesperson of the ASEA he represents the views of the 190,000 in Australia who stutter. Peter has worked as a hospital scientist for about 22 years,

giving him a good background in a wide range of health issues, including diabetes, pharmacology, drugs, genetic diseases and general pathology. He has worked in rural and metropolitan hospitals. He is the father of three children.

Margaretha Hanen OAM

Federation of Ethnic Communities' Council of Australia

Margaretha represents The Federation of Ethnic Communities' Councils of Australia (FECCA) on the Governing Committee of CHF. FECCA is the national voice of Australians from culturally and linguistically diverse backgrounds.

Born in the Netherlands, Margaretha was a social worker in Europe and in Canada helping newly settled immigrants, before coming to Australia where she taught at Flinders University for many years. During her years with South Australia's Commissioner for the Ageing, Margaretha developed some of the most innovative models of multicultural aged care that led the field on a national basis. She was a member of the Advisory Council on Multicultural Affairs that developed the National Agenda for a Multicultural Australia (1985-89).

In retirement, and until her recent move to Queensland, she has been a member of numerous committees and boards in South Australia (SA). A major involvement was a six year stint as the Chairperson of the Croatian, Ukrainian and Belarusian Aged Care Association of SA. She represents FECCA on the Australian Pharmaceutical Advisory Council and is currently establishing a community and consumer base in the Noosa Council Area.

Lou McCallum – Chairperson

Australian Council of Social Service

Lou is nominated to the CHF Governing Committee by the Australian Council of Social Services (ACOSS). Lou has worked

in non-government health organisations for many years as a policy analyst and manager. He was Executive Director of the Australian Federation of AIDS Organisations from 1996 to 1998. Lou was a co-founder and coordinator of Ankali Project in Sydney, a volunteer home-based care and emotional support service for people with AIDS and their carers. He has been on the CHF Governing Committee for eight years, as Deputy Chairperson from 1999 to 2000 and as Chairperson of the Governing Committee since September 2000.

Lou currently works as a consultant, specialising in helping governments and NGOs in resource-poor settings to establish HIV/AIDS community care services.

Russell McGowan – Secretary

Health Care Consumers' Association of the ACT

Russell is a bone marrow transplant survivor who became an active health consumer through his experiences in treatment during the early 1990s. Despite apparent cure of his original condition (myelofibrosis), he suffers consequences of treatment, a chronic condition called Graft versus Host Disease (cGVHD). This led to his early retirement from employment that had included teaching, fieldwork and policy development in community and Indigenous education and training programs.

He is the CHF representative on the Board of the Australian Council on Healthcare Standards, and various Department of Health and Ageing committees including one on bowel cancer screening, another on blood safety and quality and he participated in the most recent Radiation Oncology Inquiry.

Russell is Chair of CHF's consumer representatives sub-committee and also chairs a steering committee developing a

national Cancer Advocacy Network which is likely to seek to affiliate with CHF. Through the Health Care Consumers' Association of the ACT, Russell is also involved with projects to improve the quality of care in both the acute and primary health care sectors, including one to increase access to after hours care, and another to involve self-help groups more in the management of chronic health conditions.

David Menadue OAM

National Association of People Living with HIV/AIDS

David is the voting delegate to CHF for the National Association of People Living with HIV/AIDS (NAPWA). He is a person living with AIDS and has been involved in AIDS organisations in Victoria and nationally for over 10 years. He is currently Vice President of People Living with HIV/AIDS Victoria, Executive Member of the Victorian AIDS Council and Executive Member of the NAPWA.

He has extensive experience in health advocacy and has been a member of various Victorian Ministerial Advisory Committees on health issues, the National Caucus of Disability Consumer Organisations and the former Fairfield Hospital Board. NAPWA is keen to play a significant role in the work of CHF, particularly in issues such as arrangements for the Pharmaceutical Benefits Scheme. NAPWA is also interested in addressing issues of poverty and how the Government's welfare reforms will impact of the health and welfare of people in the community.

Mitch Messer – Vice Chair

Health Consumers' Council of WA

Mitch is Executive Director of Cystic Fibrosis Western Australia. He is President of Cystic Fibrosis Australia and Secretary of Cystic Fibrosis Worldwide. Mitch has been involved in health consumer issues in

a broader way through the Health Consumers' Council (WA) and its predecessor organisations and through the Chronic Illness Alliance in WA. During his involvement with these groups he served in the positions of Chairperson, Deputy Chair, Treasurer and Board member.

He has been involved in many committees and working groups dealing with a range of issues including aged care, pharmaceuticals, genetic services and lung transplant. He is a member of the Human Research Ethics Committee of the Fremantle Hospital and Health Service. Recently he was appointed as a member of the WA Department of Health's Genetics Council and is a Founding Member and Deputy Chair of the Genetic Support Council of WA, a new peak organisation that seeks to represent Western Australia's non-government genetic support groups.

Christopher Newell AM

Tasmanians With Disabilities

Christopher has been the nominee of Tasmanians with Disabilities to the Governing Committee of the CHF for some years. Tasmanians with Disabilities Inc. is a trans-diagnostic organisation that focuses on advocacy, policy development and self-help for, and on behalf of, people with all types of disability.

Tasmanians with Disabilities and Christopher have a broad interest in the work of CHF and issues for all consumers. Consumer rights, ethics and consumer research are several particular interest areas, as is general practice reform, and pursuing areas where personal experience as a consumer facilitates effective advocacy for consumer rights. People with a disability are a significant social grouping disadvantaged in today's society.

Christopher has been a consumer representative for many years for Tasmanians with Disabilities and other consumer bodies on a number of national

and state forums in many fields including telecommunications, rights, advocacy, ethics, education and health. He is also Chair of the CHF Editorial Committee.

Sheila Rimmer AM

Council on the Ageing (Australia)

Sheila is the immediate past National President of Council on the Ageing (Australia), known as COTA. COTA is a key national organisation that exists to protect and promote the well-being of all older people. It is an advocate for older Australians by providing information, publications, policy analysis, consultation, representation, referral and advisory services.

Sheila was born in the United Kingdom and was educated at the London School of Economics at London University and Columbia University, New York. She migrated to Australia in 1964 and worked as a tutor at the University of Tasmania and as a political commentator on television. In 1969 she moved to the University of Technology, Sydney, and later became a lecturer at Macquarie University.

In 'retirement', Sheila is a member of the Australian Medical Council and serves on the AMC Medical School Accreditation Committee, Consumers Working Group and National Evaluation Committee of the Innovative Care (Rehabilitation) Services (ICRS) Pilot. She chairs the Home and Community Care State Advisory Committee (NSW) and is on CHF's Governing and Executive Committees.

Executive Committee

The Governing Committee elects an Executive Committee, comprising the Forum's Chairperson, Vice Chair, Secretary, Treasurer and one other. The Executive is responsible for implementing the policy decisions of the Governing Committee, and for the management and finances of the Forum. The Executive

meets by teleconference once a month. During 2001 - 2002, the Governing Committee comprised:

- Lou McCallum (Chair)
- Mitch Messer (Vice Chair and interim Treasurer)
- Russell McGowan (Secretary)
- Marg Brown (to 11 June 2002)

Sub-committees & Working Parties

As a membership organisation driven by the needs and views of its members, CHF has established a range of sub-committees, steering committees, advisory committees and working parties to assist it developing its policies and responses and managing grants. The following committees met during the year:

- Consumer Representatives Subcommittee
- Membership Subcommittee
- *The Australian Health Consumer* Editorial Committee.

Management

Day-to-day management of CHF is undertaken by the Secretariat, based in Canberra. The Executive Director, Helen Hopkins, is the senior employee of the Forum and has responsibility for the Secretariat staff, day-to-day finance and administration, and other delegations and powers given by the Governing Committee. During the year CHF farewelled Matthew Blackmore, Executive Director.

As at 30 June 2002, the staff at CHF were:

- Kay Barney, Manager, Community Relations
- Angela Bright, Medicare Services Policy and Research Officer
- Melanie Cantwell, Medicines Policy and Research Officer
- Teresa Dowling, Administrative Officer
- Roselynn Klee, Finance Officer

- Justin Le Couteur, Consumer Representative Coordinator
- Yvonne Solly, Quality Use of Medicines Project Officer.

Projects

CHF welcomed a number of new staff members in 2002:

- Angela Bright joined CHF in February 2002 as Medicare Services Policy and Research Officer, working on a project to support consumer involvement in the work of the Medical Services Advisory Committee (MSAC) and raise consumers' awareness and understanding of MSAC. One of her tasks has been to compile the MSAC Register of consumer representatives, which contains details of people who have indicated their interest in potentially being a consumer representative on an MSAC Supporting Committee. Angela made initial contact with some of CHF's members and consumer representatives through the Open Disclosure Project, an initiative of the Australian Council for Safety and Quality in Health Care. CHF and the Health Care Consumers Association of the ACT hosted an Open Disclosure workshop on 4 April 2002, attended by more than 20 ACT health consumers. It was one of many that have been conducted nationally.
- The new Medicines Policy and Research Officer, Melanie Cantwell, also started in February 2002. Melanie is working on a pilot project to develop consumer input for consideration by the Australian Drug Evaluation Committee (ADEC) on selected applications for registration of new medicines in Australia.
- Yvonne Solly joined CHF in April 2002 as the Quality Use of Medicines (QUM) Project Officer. She will facilitate CHF Community Workshops around the country later this year to

share strategies consumers can use to manage their cholesterol instead of or as well as cholesterol lowering medications. The workshop consultations will be used to obtain valuable consumer advice about the barriers that consumers face when making decision about their medicines and blood cholesterol management. They will also look at the factors that underpin successful consumer health education programs at the local level.

- Justin Le Couteur joined CHF in April 2002 as Consumer Representatives Coordinator while Emma Awizen is on maternity leave. Justin met many CHF consumer representatives at the Workshop for Consumer Representatives on 27 and 28 June 2002, which looked at the Evaluation Report on the CHF Consumer Representatives Program and explored the consumer representation framework.

Staff departures

Matthew Blackmore resigned from CHF as Executive Director on 8 March 2002, but remains in touch with CHF on a regular basis as a consumer representative.

Emma Awizen is on Maternity Leave from April 2002 and she and husband Stephen are proud parents of Sophie Rose.

Rachel Stephen-Smith left CHF in July 2001 on completion of her part of the E-health project.

Contact details

Consumers Health Forum of Australia
PO Box 170
CURTIN ACT 2605

Telephone: (02) 6281 0811

Fax: (02) 6281 0959

E-mail: info@chf.org.au

Website: www.chf.org.au

Our Consumer Representatives

Health consumers are represented on 200 Government, Department of Health & Ageing, and professional and research project committees. Representatives may be sought to represent the broad interests of health consumers, or to represent CHF, sometimes alongside other consumer groups.

Consumer representatives are selected by canvassing member organisations for people with the necessary skills, experience or interest to be able to make an effective contribution to the work of the committee or working party. A Consumer Representatives Subcommittee of the Governing Committee chooses the representative from the nominations received.

CHF extends its thanks and appreciation to all consumer representatives for their dedication, enthusiasm and time devoted to the cause of consumer participation. In 2001/2002 representatives have also contributed to the review of our CHF consumer representatives program and participated in a workshop to develop our response to the review. CHF will pursue implementation of the recommendations of the review based on the input given by its representatives.

Year	No. of committees
1995/96	139
1996/97	127
1997/98	130
1998/99	118
1999/00	158
2000/01	160
2001/02	200

ACOSS and the Brotherhood of St Laurence

Working Together to Improve Dental Health Committee
Ms Kay Robinson

Australian Bureau of Statistics
Health Survey Program Advisory Committee
Ms Manoa Renwick

Australian Cancer Network
ACN Council
Ms Sally Crossing

ACN Medical and Scientific Committee
Ms Sally Crossing

ACN Non Melanoma Guidelines
Mr Malcolm Whyte

ACN Prostate Cancer Working Party
Mr Ron Halpin

Australian Cochrane Centre
Ms Ingrid McKenzie

Australian Competition and Consumer Commission
Consumer Consultative Committee
Dr Christopher Newell

Australian Council on Healthcare Standards
ACHS Board
Mr Lou McCallum (resigned)
Mr Russell McGowan

ACHS Clinical Indicator Working Parties
Ms Janney Wale

ACHS Guidelines & Indicators for Dental Services
Ms Maxine Drake

ACHS National Advisory Committee
Mr Hanno Stanojevic

ACHS Standards Committee
Mr Hanno Stanojevic

Australian Council for Safety and Quality in Health Care

Consumer Reference Group
Mr Matthew Blackmore (resigned)
Ms Helen Hopkins

Consumer Working Group
Mr Lou McCallum

Medical Device Tracking Taskforce
Ms Janney Wale

Medication Safety Taskforce
Ms Nancy Pierce

Australian Divisions of General Practice

ADGP Board Observer
Ms Sheryl Rainbird

National Divisions Forum Planning Group
Ms Kathy Mott

Australian Gastroenterology Institute

AGI Board
Mr Clive Glover

Australian General Practice Accreditation Ltd.

Board Director
Ms Kathy Mott (resigned)
Mr Matthew Blackmore

Australian Health Ministers' Advisory Council (AHMAC)

National Advisory Committee on Oral Health
Ms Kay Robinson

AHMAC Working Party on Nationally Consistent Approach to Medical Registration
Ms Dell Horey

Australian Health Care Agreements Reference Groups
Continuum of care
Mr Lou McCallum

Information technology
Ms Kate Moore

Australian Medical Council

AMC Board
Dr Christopher Newell

Education Accreditation (General)
Ms Sheila Rimmer

Education Accreditation (Specialist)
Dr Derek Weir
Ms Mary Corich

Interim Advisory Committee on the Recognition of Medical Specialities
Ms Sally Crossing
Ms Kirsty Machon

Recognition of Medical Specialities Advisory Committee
Ms Robin Toohey

Australian Medical Workforce Advisory Committee

Anaesthesia Workforce Working Party
Ms Shirley Shaw

Radiology Working Party
Ms Ann White

Australian National University

National Centre for Epidemiology and Population Health (NCEPH) Consultative Committee
Mr Lou McCallum

Australian Patient Safety Foundation

APSF Council
Ms Margaret Charlton

Australian Pharmaceutical Advisory Council

APAC
Mr Mitch Messer

APAC Subcommittee on the Intentional Misuse of Pharmaceuticals
Mr Timothy Moore

APAC Standing Committee on Consumer Medication Information
Ms Sarah Fogg

Consumers' Health Forum of Australia

APAC PBS Cost Awareness Advisory
Group

Mr Matthew Blackmore

Australian Pharmaceuticals

Manufacturers' Association

APMA Code of Conduct Committee

Ms Sarah Fogg

Australian Prescriber Editorial Board

Editorial Advisory Board

Ms Lynne Hancock

Australian Self-Medication Industry

Promotional Monitoring Committee

Dr Derek Weir

Complaints Panel

Ms Fran Hausfeld

Cancer Council NSW

Board

Ms Sally Crossing

Cancer Control Network Governing
Committee

Ms Sally Crossing

Clinical Oncological Society of Australia

Consumer Advocacy Network Steering
Committee

Mr Russell McGowan

Guidelines for Colorectal Cancer

Mr Clive Glover

Consumer Law Centre Victoria Ltd

Board

Ms Meredith Carter

Department of Health & Ageing

Australasian Cochrane Centre Review
Group Selection Committee

Ms Rebecca Coghlan

Consumer Perspectives Survey Project
Steering Committee

Mr Robert Leahy

Better Medication Management System
(BMMS)

Development Group

Ms Helen Hopkins

Better Medication Management System
(BMMS) Evaluation Working Group

Ms Sue Pluck

Better Medication Management System
Field Testing Working Group

Ms Helen Hopkins

Better Medication Management System
Hospital Working Group

Ms Judith Skinner

Better Medication Management System
Technical Working Group

Ms Sue Healy

Ms Heather Grain

Blood and Blood Product Working Party

Mr Christopher Carter

Blood Safety and Quality Working Group

Mr Russell McGowan

Bowel Screening Pilot Implementation
Committee

Mr Russell McGowan

Cancer Strategies Working Group
(National Health Priorities Committee)

Mr Clive Deverall

Chronic Disease Self-Management
Education & Guidelines Technical

Advisory Committee

Mr Lou McCallum

Consumers' Sources of Health Information
Steering Committee

Ms Sarah Fogg

Development of a National Sexual Health
Strategy Reference Group

Ms Sera Pinwall

Consumers' Health Forum of Australia

Department of Health & Ageing

Enhanced Divisional Quality Use
of Medicines (EDQUM) Program
Steering Group

Ms Nancy Pierce

Evaluation of the Australian Childhood
Immunisation Register Steering Committee

Ms Maxine Drake

GP Data Model & Core Data Set Steering
Committee

Ms Heather Grain

GP Links Amalgamation Incentives
Program Steering Committee

Ms Judith Skinner

General Practice Well-Being Project

Ms Tatiana Borisow

General Practice Immunisation Incentives
Advisory Group

Ms Irene Shaw

HealthConnect Stakeholder Reference
Group

Ms Jan Donovan

Locum Services Review Group

Ms Debra O'Connor

National Cardiovascular Health and Stroke
Strategies Group

Ms Karen Carey-Hazell

National Demonstration Hospitals Program
Steering Committee

Mr Mitch Messer

National Health Priority Action Council

Ms Hilda Bastian

National Immunisation Advisory
Committee

Ms Jenni Howlett

National Immunisation Strategy
Development Group

Ms Jenni Howlett

National Reference Group for the
Partnership Project

Mr Fred Delbridge

Neonatal Standards Working
Party

Ms Carolyn Minchin

Pharmaceutical Benefits Advisory
Committee

Mr Matthew Blackmore

Pharmaceutical Benefits Pricing Authority

Mr Geoff Honnor (resigned)

Ms Jo Watson

Podiatric Surgery Trial in Melbourne
Steering Committee

Ms Rebecca Coghlan

Point of Care Testing Sub-Committee

Ms Michele McHugh

Private Health Industry Quality Working
Group

Dr Christopher Newell

Private Health Access Taskforce

Dr Christopher Newell

Private Sector Outreach Services Working
Group

Mr Matthew Blackmore

Protheses Strategic Review Forum

Ms Karen Carey Hazell

QUM Consumer Education Advisory
Group

Mr Matthew Blackmore (resigned)

Ms Helen Hopkins

Quality Use of Pathology Committee

Ms Sally Crossing (resigned)

Ms Rebecca James

Quality and Best Practice
Advisory Group in Diagnostic
Imaging

Mr Roberto Rojas-Morales

Department of Health & Ageing

Radiation Oncology Inquiry
Mr Russell McGowan

Review of Lymphoedema Therapies
Working Party
Ms Mary D'Elia

Statutory Immunity Advisory Group
Ms Robin Toohey

Steering Committee to oversee the
implementation of the private health
insurance industry Key Feature Statement
Mr Matthew Blackmore

The National Advisory Committee to
BreastScreen Australia
Ms Sue Lockwood

Department of Human Services SA
South Australian Safety & Quality Council
Ms Pam Moore
Mr Gerald Graves

Dietitians Association of Australia
Council on Dietetic Standards Recognition
Ms Sheila Rimmer

Federal Privacy Commissioner
Privacy and Health Consumers Reference
Group
Ms Melanie Cantwell

Food Standards Australia
Board
Ms Robin Toohey

**General Practice Partnership Advisory
Council**
Consumer Standing Committee
Mr Russell McGowan
Ms Sheryl Rainbird
Ms Nancy Pierce

Divisions Subcommittee
Ms Sheryl Rainbird

Divisions Subcommittee Data Sub-Group
Ms Debra O'Connor

General Practice Education & Training

Consultative Group
Ms Robin Toohey

General Practice Computing Group

Management Committee
Ms Debra O'Connor

Electronic Health Records Architecture
Working Group
Ms Debra O'Connor

Evaluation and Monitoring
Working Group
Ms Jan Donovan

**Greater Collaboration in the area of
Primary Health and Community Care
Jurisdictional Group**

Clinical Reference Group to Consider Pre
and Post Hospital Care
Ms Betty Craig

Health Insurance Commission

Consumer Advisory Committee
Ms Amanda Cornwall
Ms Debra O'Connor

**Health Inequalities Research
Collaboration**

Primary Health Care Network
Steering Committee
Ms Pat Kopusar

Medical Services Advisory Committee

MSAC Committee
Mr Lou McCallum

Visual Electrodiagnosis Supporting
Committee
Mr Frank Fisher

Nuchal fold translucency screening
Supporting Committee
Ms Dell Horey

Near patient cholesterol testing Supporting
Committee
Mr Cyril Wyndham

Medical Services Advisory Committee

Fragile X Syndrome Supporting Committee

Ms Denise Birney

C-I-C Treatment of Hepatic Metastases Supporting Committee

Mr Russell McGowan

Rotational Atherectomy (Rotablator) Supporting Committee

Mr Ivan Kayne

Review of Magnetic Resonance Imaging (MRI) Supporting Committee

Mr Leo Pomery

Review of Transoesophageal Echocardiography Supporting Committee

Mr Richard McCluskey

Minimally invasive direct coronary artery bypass surgery - performed off pump Supporting Committee

Mr Peter Edwards

Intravascular Brachytherapy Supporting Committee

Mr Ivan Kayne

Treatment of heart failure by permanent tri-chamber resynchronisation Supporting Committee

Mr Ivan Kayne

Thrombophilia testing in pregnancy Supporting Committee

Ms Rosi Trencher

Thyrogen Supporting Committee

Ms Catherine Thompson

Viscosupplementation Supporting Committee

Ms Morice Rothstadt

Review of Technologies for Screening and Treatment of Cervical Cancer Supporting Committee

Ms Kath Mazzella

Review of Transanal Endoscopic Microsurgery Supporting Committee

Ms Shirley Shaw

Essure Device Supporting Committee

Ms Beth Walker

LeukoScan Supporting Committee

Ms Janney Wale

Review of Laparoscopic Adjustable Gastric Banding for Morbid Obesity Supporting Committee

Ms Valerie McKeown

Intra Discal Electro Arthroplasty Supporting Committee

Ms Rebecca Coghlan

Optical Biometry Supporting Committee

Mr Matthew Blackmore

Interstim Device for Sacral Nerve Stimulation Supporting Committee

Mr Lou McCallum

Endoluminal Gastroplication for the Treatment of Systematic Gastro-Oesophageal Reflux Disease Supporting Committee

Mr Lou McCallum

M-Vax Vaccine for the Treatment of Stage III Melanoma Supporting Committee

Mr Clive Deverall

Mental Health Council of Australia

National Consumer and Carer Forum

Ms Janet Meagher

National Cancer Control Initiative

A Clinical Registration Common Data Set Working Group

Ms Rosetta Manaszewicz

National Cervical Screening Program

Quality Assurance Working Group

Ms Cathy Reade

**National Health Information
Management Advisory Council**

National Decision Support
Taskforce

Ms Debra O'Connor

**National Health & Medical Research
Council**

Council

Ms Michele Kosky

Australian Health Ethics Committee

Mr Robert Griew (resigned)

Dr Bebe Loff

Australian Health Ethics Committee

Working Party on Audit/Quality Assurance
Activities

Ms Robin Toohey

Clinical Practice Guidelines for the
Diagnosis of Persistent Vegetative States

Ms Mary Baumgarten

Development of Guidelines for Water
Quality Management Coordinating Group

Mr Alec Percival

Dietary Guidelines for Older Australians
Expert Panel

Mr Frank Fisher

Health Advisory Committee (HAC)
Guidelines for the Prevention, Early
Detection & Management of Colorectal
Cancer

Mr Clive Glover

HAC Review Recommendations on
Responsible Drinking Behaviour

Mr Donald Cameron

Strategic Research Development
Committee

Ms Nancy Pierce

Xenotransplantation Working Party

Mr Twanny Farrugia

Mental Health Research Working Group

Ms Suzanne Knapman

Electromagnetic Energy Research
Committee

Mr Clive Deverall

Collaboration in Joint Health Services
Priority Driven Research

Mr David Menadue

National Heart Foundation of Australia

Cardiovascular Disease National Minimum
Data Set (CVD-NCaMDS) Working Group

Ms Dianne Spilsted

National Information Service

NIS GP Evaluation Program Advisory
Group

Ms Robin Toohey

National Institute of Clinical Studies

Emergency Department National Advisory
Committee

Ms Robin Toohey

National Prescribing Service

NPS Board

Ms Jan Donovan

NPS Information/Communication Working
Group

Ms Jan Donovan

NPS Prescribing Interventions & Feedback

Ms Rebecca Coghlan

Ms Sarah Fogg

NPS Decision Support Working Group

Ms Sue Pluck

NPS 'Medicines Line'

Management Committee

Ms Judith Skinner

National Public Health Partnership

Advisory Group

Mr Lou McCallum

Public Health Genetics Working Group

Mr Mitch Messer

National Health Priority Action Council

Examining Trauma Care
Ms Heather Grain

**Newcastle Mater Hospital Radiation
Oncology**

Re-Certification Committee
Ms Sally Crossing

**NHMRC/Newcastle Bone & Joint
Institute**

Guidelines for Acute Low Back, Neck and
Shoulder Pain
Ms Rebecca Coghlan

**Northern Territory Remote Health
Workforce Agency**

Board
Ms Liz Scott

Pharmacy Guild of Australia

Selection Committee of the Research and
Development Grants Program
Mr Stephen Gallagher
Mr Fred Delbridge

Professional Services Review

Determining Authority
Ms Michele Kosky

Quality Assurance Reference Group

Consumer Medicines Information
Ms Fran Hausfeld

**Royal Australian College of General
Practitioners**

RACGP Ethics Committee
Mr Andrew Allen

RACGP Outcomes Evaluation Advisory
Committee

Ms Jenna Bateman

RACGP Practice Standards Committee

Ms Sue Pluck

RACGP Quality Assurance and
Continuing Education

Ms Heather Johnson

RACGP Technical Reference Group -
Supplementary Guidelines for Enhanced
Primary Care Medicare Benefits Scheme
Items

Ms Nancy Pierce

Royal Australian College of Physicians

Clinical Support Systems Project
Reference Group

Mr Lou McCallum

RACP Chronic Fatigue Syndrome
Guidelines Working Party

Mr Craig Ellis

Royal Australian College of Surgeons

Australia Safety & Efficacy Register for
New Interventional Procedures – Surgical
(ASERNIPS)

Ms Wendy Brown

Royal College of Nursing Australia

Palliative Care Making the Difference
Reference Group

Ms Barbara Crane

Accreditation & Credentialling Feasibility
Study Management Committee

Ms Dawn Thorp

**Royal Australian and New Zealand
College of Obstetricians and
Gynaecologists**

Curriculum Development Committee

Ms Robin Payne

Speech Pathology Australia

Ethics Board

Mr Peter Dhu

Standards Australia

IT/14 Health Informatics Committee

Ms Heather Grain

HE/1/8 Packaging Systems & Devices
Subcommittee

Ms Mary Davies

Open Disclosure in Health Care

Ms Heather Grain

Therapeutic Goods Administration

Complementary Medicines
Evaluation Committee
Dr Heather Yeatman

Crisis Management Task Force
Dr Derek Weir

Disinfectant Working Group
Ms Jude Byrne

European Harmonisation of Medical
Devices Working Party
Ms Wendy Brown

National Drugs & Poisons Scheduling
Committee
Ms Rebecca Coghlan

Price Information Working Group
Mr Matthew Blackmore

Project Advisory Committee Electronic
Listing Facility Listing of Drug Products
Ms Karen Carey-Hazell

TGA/Industry Consultative Committee
Dr Derek Weir

Therapeutic Device Evaluation Committee
Ms Wendy Brown

Therapeutic Device Evaluation Committee
Device Tracking Advisory Panel
Ms Wendy Brown

Trans Tasman Cooperation on Therapeutic
Products Liaison Group
Mr Tony Wade

**Therapeutic Goods Advertising Code
Council**

Council
Dr Derek Weir (resigned)
Mr Alan Barclay

Complaints Resolution Panel
Dr Derek Weir (resigned)
Mr Alan Barclay

University of Melbourne

Action on Health Inequalities through
enhancing the role of General Practice
RACGP Reference Group
Ms Tatiana Borisow

**University of Queensland – Centre for
General Practice**

Single Patient Trials Service Reference
Group
Ms Glenda McChesney-Clark

University of Queensland

Musculoskeletal Medicine
Review Panel
Ms Rebecca Coghlan

University of Newcastle

NHMRC Drug Industry & Professional
Behaviour
Steering Committee
Mr Matthew Blackmore

**University of NSW Centre for General
Practice Integration Studies**

Divisions & Hospitals Integration Program
Mr Cyril Wyndham

**University of SA and University of
Sydney Departments of Pharmacy**

Implementation of Pharmacy Standards for
S2/S3 Medicines
Ms Kathy Mott

Our Members

CHF comprises a wide variety of consumer organisations, representing a broad range of health consumers such as illness groups, disability groups and specific population groups such as youth, older people and women. CHF comprised 102 Voting members and 157 Associate members in 2001/2002.

Voting members

Voting members of CHF are organisations that:

- represent consumer and community opinions and do not act primarily as representing professional, provider or commercial interests
- has membership open to consumers who can be elected to the board or governing body of the organisation
- has aims and objectives that are significantly for representation of the opinions of consumers
- fully support the aims and objectives of the Consumers' Health Forum.

A

ACCESS Australia National Infertility Network Ltd
ACT ME/CFS Society Inc
ACT Repetitive Strain Injury Support Group Inc
Action Research Issues Association Inc
AIDS Council of NSW
Allergy and Environmental Sensitivity Support and Research Association
Arthritis Foundation of Australia
Arthritis Foundation of Victoria Inc
Asthma Australia
Australian Association for the Welfare of Child Health
Australian Breastfeeding Association
Australian Chemical Trauma Alliance Inc
Australian Complementary Health Association
Australian Council of Social Service
Australian Crohns and Colitis Association
Australian Federation of AIDS Organisations

Australian Hepatitis Council
Australian Intravenous League Inc (AIVL)
Australian Mental Health Consumer Network
Australian Multiple Birth Association
Australian Pensioners' and Superannuants' Federation
Australian Quadriplegic Association
Australian Speak Easy Association
Australian Women's Health Network

B

Breast Cancer Action Group (NSW)
Breast Cancer Action Group Inc
Breast Cancer Network Australia

C

Carers Australia
Child Health Association Inc
Club SPERANZA
Coeliac Society of NSW Inc
Continence Foundation of Australia Ltd
Council on the Ageing (Australia)
Council on the Ageing (SA)
Country AIDS Network (Vic) Inc
Cystic Fibrosis Association of Victoria Inc
Cystic Fibrosis Australia Inc
Cystic Fibrosis WA

D

DES Action Australia – NSW
Diabetes Australia
Diabetes Australia – ACT
Diabetes Australia – NSW
Diabetes Australia – Queensland
Diabetes Australia – SA
Donor Conception Support Group of Australia Inc
DSP Australia Inc.

E

Eating Disorders Association of SA Inc

F

Federation of Ethnic Communities' Council of Australia

G

Geelong Mental Health Consumers Union

H

Haemophilia Foundation Australia
Headway Victoria
Health Care Consumers' Association of the ACT
Health Consumers Network (NSW) Inc
Health Consumers of Rural and Remote Australia Inc
Health Consumers' Council WA (Inc)
Health Issues Centre
Health Rights & Community Action
Heart Support – Australia
Hepatitis C Council of NSW Inc
Hornsby Ku-ring-gai Association Action for Mental Health
Hunter Urban Network for Consumers of Healthcare

L

Lower Hunter Health Council

M

Maternity Coalition Inc
ME/CFS Society (SA) Inc
ME/CFS/Fibromyalgia Assoc. QLD
Medical Consumers Association NSW
Mental Health Association QLD Inc
Mental Health Association NSW Inc
Mental Health Co-ordinating Council
MS Society of Victoria

N

National Association of People Living with HIV/AIDS
NODSS – Narcolepsy & Overwhelming Daytime Sleep Society of Australasia Inc
Northern Rivers ME/CFS/FM Support Assoc Inc

O

Obsessive Compulsive Disorders Support Service
Older Persons' Action Centre
Older Women's Advisory Committee (SA)
Older Women's Network Inc (NSW)

P

Palliative Care Australia
People Living with HIV/AIDS (NSW) Inc
Post-Polio Network (NSW) Inc
Public Interest Advocacy Centre

Q

Queensland Council of Social Service
Queensland Rural Women's Network Inc
Queensland Women's Health Network Inc

S

Schizophrenia Fellowship of SA
Self Help Queensland Inc
Shellharbour District Community Health Watch
Shoalhaven North Health Consumers Action Group
SIDS Australia
Sleep Apnoea Association
South Australian Consumer Reps Network
South Australian Council of Social Service
Stillbirth and Neo-natal Death Support (Qld) Inc
Support & Advocacy Committee of Prostate Cancer Foundation of Australia

T

Tasmanians with Disabilities Inc
The Link Youth Health Service
Top End Division of General Practice
Consumer Reference Group
TRANX

V

Victorian Mental Illness Awareness Council Inc

W

WA Association for Mental Health
Wollongong Health Consumers Advisory Group
Women's Health Victoria Inc

Associate Members

Associate members of CHF are professional and service organisations that support the aims and objectives of CHF.

A

Aboriginal & Islander Community Health Service
Adelaide Central Community Service
Alison Hunter Memorial Foundation
Alliance of NSW Divisions Ltd

Consumers' Health Forum of Australia

Anti-Cancer Foundation of South Australia
Asthma Victoria
Australian Nursing Homes & Extended
Care Association
Australian Association of Consultant
Pharmacy
Australian Cancer Society
Australian College of Health Service
Executives
Australian College of Midwives Inc
Australian Crohns & Colitis Association
(Qld) Inc
Australian Institute of Health & Welfare
Australian Nursing Council Inc
Australian Nursing Federation (Vic
Branch)
Australian Physiotherapy Association
Australian Physiotherapy Association
(NSW)
Australian Self-Medication Industry Inc –
ASMI

B

Ballarat & District Division of General
Practice
Brisbane Southside Central Division of
General Practice

C

Canning Division of General Practice Ltd
Canterbury Division of General Practice
Carers Association of Victoria Inc
Central Highlands Division of General
Practice
Centre for Health Services Research

D

Darebin Community Health Service Inc
Doctors Reform Society NSW Inc

E

Enduring Solutions Pty Ltd

F

Family Planning Australia Inc

G

General Practice Divisions of Western
Australia
GlaxoSmithKline

Goulburn Valley Division of General
Practice
GP North
Greater Bunbury Division of General
Practice

H

Health Consumers Voice (NT)
Health Department of WA
Health Development Unit, Community
Health Service
Health Strategy & Acute Services, ACT
Dept of Health and Community Care
Healthy Cities Illawarra
Hornsby Ku-ring-gai Ryde Division of
General Practice

I

Illawarra Division of General Practice
Ipswich & West Moreton Division of
General Practice

J

Janssen-Cilag/Johnson & Johnson

L

Liverpool Women's Health Centre

M

Mackay Community Health Centre
Mallee Division of General Practice
ME/CFS Society of Victoria Inc
Mornington Peninsula Division of General
Practice

N

National Asthma Campaign
National Heart Foundation
North East Valley Division of General
Practice
North East Victorian Division of General
Practice
North West Melbourne Division of
General Practice
North West Tasmania Division of General
Practice
Northern Metropolitan Community Health
Service
Northern Queensland Rural Division of
General Practice

Consumers' Health Forum of Australia

Northern Rivers Division of General Practice
Northern Sydney Area Health Service
NSW Central West Division of General Practice
NSW Nurses' Association
NSW Therapeutic Assessment Group Inc
Nurses Board of Victoria

P

Paraplegic & Quadriplegic Association of Qld Inc
Pfizer Pty Ltd
Pharmaceutical Society of Australia
Pharmacy Guild of Australia

Q

Queensland Cancer Fund

R

Redcliffe Bribie Caboolture Division of General Practice
Royal College of Nursing, Australia
Royal Flying Doctor Service (Australia Council)
Rumbalara Aboriginal Cooperative
Rural Doctors' Association of Australia

S

SA Diabetes Consumer Reference Group
Sherbrooke Pakenham Division of General Practice
Social Work Dept, Royal North Shore Hospital
Society of Hospital Pharmacists of Australia
South East NSW Division of General Practice
South Western Sydney Area Health Service
Southern Area Health Service
Southern Child & Adolescent Mental Health Service
Southern Division of General Practice
Southern Tasmanian Division of General Practice
Speech Pathology Australia
St George District Division of General Practice
St Joseph's Hospital

Sunshine Coast Division of General Practice
Sydney Counselling Centre
Sydney Legacy Appeals Fund

T

The Pharmaceutical Alliance
Toora Single Wimmin's Shelter
Top End Division of General Practice

W

Wentworth Area Health Service
West Victorian Division of General Practice
Westgate Division of Family Medicine
Women's Health West
Women's Health Queensland Wide Inc

Y

Yarra Valley Division of General Practice

CHF also has 60 individual associate members.

**Financial Report for the year
ended 30 June 2002**