

# Hep C factsheets

## Council history



### The beginning

### National development

### NSW consolidation

### A new decade of service delivery

### Review and improvement

### The future

### Also see

## The beginning

The identification of the hepatitis C virus in 1989 established a new era in the scientific understanding of hep C. In stark contrast, people affected faced confusion and ignorance about their condition. A need for community-wide information and support was clearly visible.

Professor Geoffrey Farrell of Westmead Hospital recognised this need. His assistance and the commitment of the group's inaugural President, Ms Audrey Lamb, enabled the establishment of a patient support group that inaugurated in November 1991 as the NSW Hepatitis C Support Group.

A toll-free 1800 support line involving a network of metropolitan and non-metropolitan volunteer telephone counsellors was established, the first hep C information pack was produced and distributed to callers and health care professionals and advocacy activities began in earnest.

## National development

Recognising that similar information and support needs existed across all Australian states and territories, and with the involvement of people in Western Australia, Victoria and New South Wales, the group became incorporated in February 1993 as the Australian Hepatitis C Support Group, gaining the status of a registered charity.

While remaining committed to client support services, the group increasingly began to address public and peer education and Federal issues, including access to interferon treatment and social security pensions. Networking with peer health and welfare based agencies also increased considerably.

Applications for federal funding were rejected and the group could not function on a national level. In July 1994, the Australian Hepatitis C Support Group reformed as the Hepatitis C Council of NSW, moving to its first offices at Belmore St, Surry Hills in Sydney.

## NSW consolidation

1994 also marked the NSW Health Department's formal acknowledgement of the Council's role by providing ongoing funding for the provision of information and support services. This marked the beginning of a shared commitment to address hep C needs within NSW.

In October 1994, NSW Health convened a state HCV Taskforce to identify gaps in hep C health care provision and propose strategies to fill such gaps. The Council was invited to sit on this taskforce along with other community-based groups and government departments.

In December 1994, the Council relocated to more suitable office accommodation in Crown St, Surry Hills, where we remain. In 1995, NSW Health approved further funding as a contribution to our core operating costs and to expand our information and support services. We were able to further professionalise the *Hep C Helpline*, by initiating in-house operation of the service from our office,

formalising the volunteer worker training program and expanding the hours of operation.

From 1995 to 2000 we remained fully involved with representing the hep C-affected communities through our membership of the NSW Hepatitis Advisory Committee (later the Ministerial Advisory Committee on Hepatitis), various Federal government consultation groups, the ANCARD Hepatitis C Sub-Committee, a range of NSW Area Health Services' strategic planning committees, HepCare and Hepatitis C Demonstration Projects.

In 1998/99 we played a major role in the NSW Parliament's Standing Committee on Social Issues Inquiry into hepatitis C. *Hepatitis C: The Neglected Epidemic*, the bipartisan Inquiry report tabled in NSW's Legislative Council in November 1998, found that the social impact of hep C is profound and touches every facet of community life.

In 1999 a welcome funding increment from NSW Health enabled us to include a formal policy and community development role as well as consolidate and improve our service delivery and administrative systems.

During 1999/2000 the Council made major contributions to the development of the first NSW and first National Hepatitis C Strategies. A range of welcome hep C projects funded under the Public Health Outcomes Funding Agreements - Incentive Projects enabled NSW to work towards further reducing the impact of hep C on those it affects.

The Council piloted and developed an innovative health care worker education strategy. This informed a major workforce development project being led by NSW Health that has enhanced the capacity of health services to better meet the needs of people living with or at risk from hep C infection.

## A new decade of service delivery

The 2000/2001 year saw significant expansion in community responses to addressing the epidemic.

The Council's role in the planning and operation, through a greatly expanded *Hep C Helpline*, of the world's first mass media hep C public awareness campaign in March 2000 was important in ensuring community input remained at the forefront of the public health partnership response to hep C.

We worked in close partnership with the NSW Anti-Discrimination Board and other stakeholders in the world's first inquiry into hep C-related discrimination. The resulting report, *C Change*, informs ongoing access and equity improvements within the health workforce, general workplace and wider community.

Funding increments both by NSW Health and the Commonwealth Department of Health and Aged Care meant that in 2001/2002, the Council was able to and provide enhanced education and capacity building services across NSW.

This led, in early 2001, to the establishment of the *Heplink* hep C related health care worker network and the *C-eeen & Heard* positive speakers service. Soon afterwards, in collaboration with the NSW Department of Corrective Services the Council established the *Prisons Hep C Helpline*.

In an effort to foster better peer support across NSW, in September 2003, the Council launched the *HepCAustralasia* internet forum (then called *Hep C NSW*).

November 2004 saw the Council, as a health promotion charity, achieve Deductible Gift Recipient Status through the Australian Tax Office. This enabled individual donors to make tax exempt donations to the Council.

In June 2005, our Media Speakers Service was launched. This project involved recruiting people living with hep C who were prepared to tell of their experience on television and radio and in print media. The volunteers were provided with media training and professional support.

# Hep C factsheets

## A Council history

In a move that promoted increased responsiveness and a heightened level of information provision, in June 2006, the *Hep C Helpline* was restructured so that Council paid staff handled all calls.

In March 2007 the Council launched *Hep Connect*, a peer support program enabling people to speak by phone with trained volunteers who have experiences of living with hep C, including treatment.

In March 2007 the Council received a welcome and ongoing enhancement to our core grant from NSW Health. This enabled a major review of our website, the continuation of the *Hep Connect* peer support project and the appointment of two additional project staff. The new positions enabled the expansion of the Council's information and resources capability, and of our workforce development capacity, and took the Council's staff complement to twelve.

The Council continues to involve volunteers in a range of ways. In most years we engage up to 100 regular and occasional volunteers in a variety of roles: from serving on our Board of Governance, through helping with mass mailouts of our magazine and other resources, and to providing peer support through our *Hep Connect* program.

### Review and improvement

To ensure that overall strategic direction remains in line with the needs and aspirations of our membership and other members of the affected communities, we conduct regular community and stakeholder consultations and service reviews.

Surveys, interviews and focus groups, and consultations with our volunteers, Board members and staff are the processes we use to inform the ongoing process of strategic planning and subsequent, more detailed business planning. They guide our work and help ensure our Council remains responsive, accountable and effective.

These formal processes were first carried out in 1997, again in 2003 and most recently in 2006.

Adding to our planning processes, a major achievement of the Council in 2002/03 was the completion of an internal and external review for accreditation by the Quality Improvement Council of Australia. We received formal notice of accreditation in July 2003. In March 2006, the Council undertook another review and was again awarded a three-year accreditation in June 2006.

In line with our Quality Improvement Council commitments, in July 2007 we attained the international Health On the Net (HONcode) accreditation for our website.

### The future

The Council remains strongly committed to fulfilling its mission and to meeting its goals. These are described in our Strategic Plan 2006-2010, available from the Council directly or via our website.

Our five priority work areas ensure the Council is well placed to help address the needs of people in NSW with hep C, to help reduce the ongoing unacceptably high hep C transmission rates and to help reduce the impact of the epidemic as whole.

### Also see

*Australian snapshot* (factsheet)

*Council overview* (factsheet)

Hepatitis C Council of NSW *Strategic Plan 05-10* (downloadable from our website)

Early editions of *The Hep C Review* (magazine)

- This factsheet was developed by the Hepatitis C Council of NSW.

This factsheet was produced by the Hepatitis C Council of NSW and was last reviewed in Jan 2008

*Hep C Helpline* and *HepConnect* (peer support): 02 9332 1599 / 1800 803 990

Web info: [www.hepatitisc.org.au](http://www.hepatitisc.org.au) Web peer support: [www.hepcaustralasia.org](http://www.hepcaustralasia.org)

The Hepatitis C Council of NSW Inc is a community-based, non-government organisation, funded by the NSW Health Dept.