

Welcome to the first Joondalup Family Health Study newsletter! This newsletter – in conjunction with mail-outs, our website (www.ifhs.org.au), community events and our telephone hotline (1800 783 110) – is a way for the Study team to keep you informed and up-to-date with the latest JFHS news.

2006 promises to be a very busy year for the JFHS team. Taking the Joondalup Family Health Study from an idea and turning it into reality involves a great many interlocked steps – each of which is individually very important.

Generating a strong partnership with the Joondalup community is our paramount focus, so the [Community Engagement Program](#), which began late last year, will continue well into 2006. Put simply, the aim of this phase has been to assess whether there is sufficient support from the Joondalup community for a proposed Family Health Study in the area, and to answer any queries or concerns that you as a community may have. So far, we have briefed key stakeholders including local and Federal Government representatives, State Government departments, consumer groups and Joondalup health care institutions.

We have also carried out comprehensive surveys and held a Community Forum with Joondalup residents. Over 7,000 randomly-selected Joondalup residents were sent a detailed questionnaire about their views on the proposed Study, and over 1,200 (16%) responded. In addition, the JFHS team surveyed every resident who took part in the Community Forum. The community support evident from the Forum and these surveys has been overwhelmingly positive, so we're extremely excited about moving forward with the project. For example, 96% of people surveyed believed it was very or quite important to conduct large-scale family health studies, with 85% of residents stating they were very or quite interested in participating in the Study.

On top of this, 85% of parents were very or quite likely to allow their children to participate, and most people expected the benefits of the Study to be realized more by later generations, but also quite strongly by themselves.

The survey showed that the main motivating factors for people to take part included regular free medical testing offered by the Study, the potential to contribute to the development of new cures, treatments and screening techniques for diseases, as well as the need to aid the long-term efficiency of the health system.

In addition to revealing the high level of community support for the Study, the survey results have played a key role in the design of the Study itself. For example, 77% of people preferred that the privacy and protection of personal data be the responsibility of the medical research community rather than the Government. As such, it is the plan of the Study to work with ethics committees at the University of Western Australia (UWA) and Edith Cowan University (ECU), as well create the Joondalup Family Health Study's own independent Ethics Oversight Committee, to govern this area.

A full report of the community engagement initiatives undertaken thus far is available on the JFHS website [here](#).

Given this level of support, it is likely that the Study will go ahead, although no decision will be made until the Community Engagement Program is completed. On this basis, we are currently working to secure funding for the Study, by applying for grants from national research funding bodies. Later, the JFHS will also apply for human research ethics committee approvals from UWA and ECU.

As for the future, many more exciting community events are planned this year. For example, we plan to host an educational schools event, conducted in conjunction with Edith Cowan University Joondalup. This schools-based launch plans to invite school students from the City of Joondalup to participate in an interactive and informative day involving debates, discussions and information on the Study. This gives the Study team the opportunity to engage with the youth in the community and to highlight how the JFHS is being designed for present, and future, generations.

In conjunction with the Department of Health and Scitech, we are also pleased to be co-hosts of the annual state-wide genETHICS essay competition. This innovative competition aims to encourage Western Australian secondary school students to explore the ethical, legal and social dimensions of a hypothetical situation resembling the Joondalup Family Health Study. Further to this, there will be a special focus on encouraging Joondalup-area secondary school students to take part in this competition.

In addition, as part of our ongoing community engagement program, we plan to host information evenings, information stands at local shopping centres and libraries, sausage sizzles and many other events to give the community every opportunity to meet the Study team and to ask any questions they may have.

These are just some of the events we look forward to hosting this year. Participants in the Forum last year provided some excellent suggestions for further community events and many of these have been taken up by the Study team. However, if there any events which *you* would particularly like to see happen, or there is something you would like to discuss with a member of the Study team, please do not hesitate to let us know by emailing us at queries@ifhs.org.au or telephoning our toll-free number on 1800 783 110.

Thank you and we look forward to speaking further with you soon.

Best wishes,

The Joondalup Family Health Study Team