# Know your genes: A study of programs that provide information about genes and inherited conditions

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# Declaration

This sub-thesis is the original work of Natalie Joy Roberts, and all sources have been acknowledged.

Signed Natalie Roberts Date 22/6/99

# Abstract

Research into hereditary disease is moving at a rapid rate. More and more medical conditions are being attributed to genetic mutations, and some members of the public are being urged to undergo screening tests to assess their risks of developing a genetic condition, so that preventative measures can be taken.

If these people are to understand what is happening to them, they need clear and accurate information. So too do the general public, if they are to be supportive of those affected and able to participate intelligently in discussion about the future of genetic testing and research.

Is there sufficient information for those affected by genetic conditions to make informed decisions about their participation in genetic testing? Is enough effort being made to inform the general public of developments in genetic research? Are the interests and needs of each group being considered when information is designed and communicated? If the answer is no, where might improvements be made?

This sub-thesis addresses the questions posed above, and examines several education and awareness programs in operation in Australia and worldwide. The programs were compared and contrasted, to highlight strengths and weaknesses and develop strategies for improving communication in this vital area.

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# An explanation of some of terms

The term **program** will be used to describe an overall educational effort, made up of many individual components, run by a particular organisation or committee. Examples include the NSW Genetics Education Program, the Association of Genetic Support of Australasia, or an education program within a clinical genetics unit.

A **project** is considered to be an individual effort to raise education or awareness, carried out with a distinct function and organisation. For example, the NSW GEP had an internet site, and published the *Genetics Resource Book* in 1998 (see Chapter 3). Each of these is considered a project.

Genetics **education** will be used in this study to refer to the actual learning of facts or ideas about genetic diseases or testing. Alternatively, genetics **awareness** describes general knowledge about genetics or of the existence of conditions, tests or services, even though specific details may not be fully known or understood. It may also include some knowledge of where to look for information. A distinction is drawn between education and awareness because it is desirable in many cases simply to raise awareness; attempting to educate may be too difficult and may not be the point of the project/program.

Genetic **testing** refers to the analysis of human DNA, RNA, chromosomes, proteins, and certain metabolites to predict disease risk, identify genetic carriers, and establish prenatal and clinical diagnosis or prognosis (Holtzman and Watson, 1997). These tests include prenatal, newborn and carrier screening, and testing in high-risk families, but exclude tests for mutations that were not inherited (i.e. developed over the course of the patient's life).

In genetic **screening**, large groups of asymptomatic people are genetically tested to see whether they are carriers of a particular disorder.

# Chapter 1: Introduction

Medical science is making rapid progress in the development of sophisticated laboratory techniques for characterising the human genome. Almost every day we hear of another disease which has been attributed to faulty genes. There is an ever-increasing number of tests available to detect whether a person or foetus will be affected by an inherited condition, and individuals and families must make decisions as to whether to undertake these tests, and what test results will mean for them.

Effective communication programs need to exist if society is to fully understand the implications of hereditary disease. As developments arise in genetic research, there must be reliable sources to put the new information into context and distribute it. Those affected by genetic conditions require the most accurate and useful information possible. Services such as diagnostic tests and genetic counselling are available for those in need, but first the public must be made aware of them.

In mid-1997, my family discovered we have a history of hereditary haemochromatosis (HH), an iron storage disorder that can be fatal if not diagnosed and treated early. Wanting to find out more about the disease, my mother asked her general practitioner (GP) for information, but received no explanation and was vaguely told of some pamphlets which she was never given. She had no idea of where to look next, having never had to deal with such an issue before. It concerned me that the doctor knew so little about such a common disorder. Current estimations are that HH affects one in 300 people of Caucasian ancestry, with as many as one in ten people carriers of the disease (NSW Genetics Education Program, 1998a). It was even more alarming that the GP was so vague about the disease in light of the fact that HH is a condition that if diagnosed and treated early, has few ill effects.

This led me to wonder what sort of information exists for GPs, affected families, and the general public. Did our GP know little about HH because there was no information available, or was she not aware of it? Are there places my mother could look for information herself, rather than relying on the GP?

The research question that followed on from this was:

*Is information about genetic diseases and testing readily available and suited to the needs of the target audience(s)?*

If there was information, who was responsible for it? What did they provide, and how was it delivered? Was it tailored to meet the needs of the particular groups who would use it? If there were some deficiencies in certain areas, how could they be overcome?

## Research Method

There are several places one might look for information about genetic conditions like HH. These are the places where medical information is usually most readily available, such as doctor's surgeries, pharmacies, the telephone book, the internet and the library. All of these, except perhaps the internet, are readily accessible to most of the population.

Each of these locations was visited, and sources of information about hereditary conditions identified. Several of these were then selected for further analysis, the main one being the main provider of information in New South Wales, the NSW Genetics Education Program.

This study considered the provision of information and its delivery to the public from the point of view of the information provider. Interviews were conducted with staff from three information sources located in NSW, and they supplied much of the information analysed. The remaining programs were accessed via articles in refereed journals, or evaluations that were written by the project coordinators. Some information came from the internet.

This approach allowed for access to evaluations and surveys already conducted and reported by the coordinators of the projects. How accessible the information provided by the programs was to the public was considered in the relevant chapters.

For the purposes of the study, it was considered that there are two main audiences - the *interested public* and the *general public*. The interested public are those people who are affected personally, or have a family member or friend who has or potentially has a genetic condition. It includes those who want to undergo genetic testing. They are motivated to find out about genetic conditions because of a personal interest. Included in the interested public are the health care professionals who work with those affected by genetic conditions, including doctors, nurses, social workers, paediatricians and genetic counsellors. They have a professional interest in learning about genetic conditions and testing.

The general public encompasses the rest of the population, those people without a direct need to know about genetic conditions but who may have a general interest in learning about current research findings or treatments. This group includes teachers, students and the media, all of whom at some time may need information but not because of a personal contact with an affected person. Those adults considering having children are also included in this group, as many of them may be unaware that the option exists for prenatal genetic tests or carrier screening.

It is important to distinguish between these two audiences at the outset because it is possible that their different needs and interests will determine their receptiveness to different forms of information. It is likely that for the general public, raising awareness will be the most important outcome, while the interested public may require detailed information.

## Desired aims and outcomes

The main aim of the study was to answer the research question posed above. Once that question had been answered, it was hoped the research would identify the most successful methods of educating or raising awareness. Suggestions could then be made as to the best ways to tailor communication to the particular audience. Future communication strategies could then incorporate some of the ideas into their efforts.

## Significance of the study

A study such as this has not been carried out before. Members of the NSW GEP were analysing their own efforts as this sub-thesis was being written, but it was not an independent study, nor did it consider other programs and how they might compare.

The following chapter describes further reasons why research is needed into the future of information provision about genetic conditions and testing. A review of the literature suggests that both the general public and the health care professionals lack knowledge about hereditary diseases and where information can be found. Academics and health care professionals alike agree there is a need for more awareness projects (Roberts, 1990; Harper, 1992; Danks, 1993b; Garver *et al*, 1993; Olopade, 1996; Richards, 1996a) which points to the necessity of this study to investigate the current climate and how it might be improved.

# Chapter 2: Literature Review

## Introduction

The influence of our parents on the way we look has been known for years. Even before Mendel's famous pea plant experiments were published in 1856, certain traits were known to be "in the blood". Sayings such as "she has her father's eyes" or "he gets that from his mother's side of the family" have been around for a long time, and while those who exclaimed them did not know about genetics as we do today, they knew that somehow parents influenced more than just their child's upbringing (Richards, 1996b).

It is not just our looks that we have inherited from our parents. Genetic makeup can also have a large influence on our body's health. Over 6000 disorders have been identified as being due to malfunctions in single genes (Association of Genetic Support of Australasia, 1997). Many of these have for years been known to have a genetic basis, including the well-known blood clotting disorder, haemophilia. Records from the time of Queen Victoria show the appearance of the disease in Victoria's children, which was passed down through many generations.

It has come to the point that many now believe genetics plays a role in most diseases afflicting the western world. As Davison, Mcintyre and Davey Smith (1994, p340) said, "There is a genetic factor in many, if not all, of the common chronic diseases accounting for the bulk of adult mortality and disease burden in industrialised countries." It is a research field that continues to grow (Harper, 1992; Garver, LeChien and Henderson, 1993), bringing with it a huge number of ethical and social issues. Recent estimations are that one in ten Australians will be adversely affected during their lifetime, directly or indirectly, by a genetic condition (Association of Genetic Support of Australasia, 1997).

There are currently over one hundred genetic diseases for which tests are routinely carried out in Australian diagnostic laboratories (Human Genetics Society of Australasia, 1998b). They include cystic fibrosis (CF), HH, Duchenne muscular dystrophy, fragile X, hereditary breast cancer, haemophilia, inherited Alzheimer disease, Huntington disease, Tay-Sachs disease, thalassaemia, and phenylketonuria.

## Why educate?

For society to understand and make informed decisions as a result of their personal contact with genetic diseases, and about the direction of genetic testing and hereditary disease management as a whole, better education and awareness is essential. As genetics becomes more relevant to health care, more physicians and health care providers will become involved, pointing to a need for professional education about advances and new technologies (Garver *et al*, 1993).

The advantages of a well-informed society are multiple. With the ever-increasing number of genetic tests becoming available, it is important that those who can utilise them are aware of their existence (Richards, 1996a). As Danks (1993b, p221) says "We have made genetic counselling and tests for prenatal detection of serious defects available to those who seek them. It is time to start drawing them to the attention of those to whom they are relevant." There is evidence to suggest that access to education and counselling is one of the biggest barriers to the use of genetic services (Olopade, 1996). A recent study has suggested that even many GPs are not aware of the availability of genetics services (Stephenson, 1997), an issue which is addressed later in this chapter.

The 1993 Nuffield Council on Bioethics stated that an educated public will be better equipped to make informed decisions about undergoing genetic testing and screening (as cited in Turney, 1995). Whether to undertake testing may be a difficult decision. It might be influenced by emotions, other people, or by practicalities such as whether, if it is prenatal testing, the parents are able to cope physically, financially and emotionally with the birth of an affected child (Gerber, Pearn and Bell, 1985; Williamson, Allison, Bentley, Lim, Watson, Chapple, Adam and Boulton, 1989; Roberts, 1990; Workshop on Population Screening for the Cystic Fibrosis Gene, 1990; Mennie, Liston and Brock, 1992; Scriver and Fujiwara, 1992; Danks, 1993a; Elias and Annas, 1994).

Understanding the genetic basis of a disease, how it came about, what it means for other members of the family, and most of all, what it means for the affected person, will make decision-making easier. Rational decisions will be made when those involved are fully informed (Haan, 1993; Victorian Government Department of Human Services, Public Health Division, 1998).

Even if an informed decision has been made, other people can be judgemental if they are not aware of all the facts and issues involved. This is likely to occur to a

greater degree when there is little understanding about the effects of a genetic condition or the implications of a test result. If the general public is educated about the advantages and disadvantages of testing, and are able to respect a person's choice, even if it may not agree with their own ideas, there will be less stigmatisation and discrimination (Collins and Schimke, 1991; Haan, 1993; Victorian Government Department of Human Services, Public Health Division, 1998). This is something which has been demonstrated (Harper, 1992).

Community screening for carriers of genetic disorders may soon be commonplace (Roberts, 1990; Nowak, 1994), and it is extremely important that screening programs are accompanied by effective education projects (Roberts, 1990; Harper, 1992). This was voiced strongly by Michael Kaback, of the University of California (as cited in Roberts, 1990, p19), who said "Screening without education and counselling would be a catastrophe".

In the last few years, mail order testing services have become available in the United Kingdom (Harper, 1995). A saliva sample is posted to a diagnostic laboratory, which returns a result and some written information (Harper, 1995). Such testing bypasses the usual education and counselling offered prior to screening, and has the potential for causing quite serious psychological problems. Professional opinion is that information and counselling is an integral part of genetic testing (Harper, 1995). With services such as mail order testing available, it is even more important the community be knowledgeable, because the regular sources of information (e.g. GPs, genetic counsellors) may never be consulted. The producers of the test argue that there is sufficient information given out, even though face to face counselling is never obtained (Cuckle, Lilford, Wilson, and Sehmi, 1995).

A side effect of the developments in genetic tests is the legal action which started appearing about fifteen years ago against a variety of people for their failure to point out the availability of, or utilise, genetic testing and alternate reproductive options (Gerber *et al*, 1985; Carrasco, 1996). There have been cases involving disabled children suing their parents, physicians or genetic counsellors for having been born with a congenital disability. This is known as "wrongful life". More common is parents taking action against health care professionals such as doctors and paediatricians for failing to draw their attention to the availability of prenatal tests, or for not informing them adequately of their options, a case known as "wrongful birth" (Gerber *et al*, 1985). Such cases may be able to be avoided if the availability of the tests is more widely advertised.

There is a need for guidelines and laws governing the use (and abuse) of genetic testing and the results (Holtzman, 1980), especially with regard to access by insurance companies and employers (Harper, 1992). There must be input from an informed public, with open discussions and debates involving the public and professionals (Harper, 1992; Turney, 1995; Kerr, 1996; Richards and Ponder, 1996; Victorian Government Department of Human Services, Public Health Division, 1998).

Many geneticists, social scientists and science communicators have stressed the need for improvements in public awareness of genetics, and called for more education programs (Roberts, 1990; Harper, 1992; Griffiths, 1993; Turney, 1995; Durant *et al*, 1996; Kerr, 1996). Durant *et al* (1996, p236) sum up the feelings of many in their simple statement about the importance of awareness of genetics: "...it is in the interests of health care professionals, patients and the general public that greater attention should be paid to the public understanding of the new genetics." The new genetics in this context refers to genetics as it applies to medical science, and includes hereditary disease as well as advances in gene technology.

## Is there support for the development and use of genetic testing and therapy?

In the United States of America (USA), about two-thirds of surveyed representatives from patient organisations, industry and the scientific community believed society will benefit greatly from the medical applications of biotechnology, including genetic testing and gene therapy, in the next twenty years (Genetics and Public Issues Program, 1998).

The survey found that 93% of Americans approved of using genetic information for early diagnosis of disease, and 88% approved the use of tests identifying carriers. Eighty-seven percent felt correcting genes that cause serious disease was ethical.

Several other studies found similar results to the one described above, with most people demonstrating a very positive attitude towards genetic testing. A number of researchers focused on attitudes toward carrier screening for diseases like CF, finding that the majority of people interviewed believed knowing their genetic status was beneficial, even if many would not alter their reproductive behaviour (Williamson *et al*, 1989; ten Kate and Tijmstra, 1990; Cobb, Holloway, Elton and

Raeburn, 1991; Scriver and Fujiwara, 1992; Croyle and Lerman, 1993; Mitchell, Scriver, Clow and Kaplan, 1993; Hietala, Hakonen, Aro, Niemala, Peltonen and Aula, 1995; Julian-Reynier, Eisinger, Vennin, Chabal, Aurran, Nogues, Bignon, Machelard-Roumagnac, Maugard-Louboutin, Serin, Blanc, Orsoni and Sobol, 1996).

With a widespread consensus such as this about the value of knowing about one's genes, and using this information for medical purposes, the growth of the area, and the need for further public education, looks likely to increase.

## Current genetics knowledge

### The general public

A number of studies have been undertaken to find out just how much or how little the lay public knows about genetics and genetic disease. The majority of these found that most people knew very little (Williamson *et al*, 1989; Harper, 1992; Griffiths, 1993; Kerr, 1996; Olopade, 1996; Richards, 1996a; Richards and Ponder, 1996). Even women who had undergone genetic counselling were found not to fully comprehend such things as the risk of giving birth to affected children (Parsons and Clarke, 1993).

In a 1990 survey conducted in the USA, only 13% of respondents reported having a "great deal of knowledge" about genetic screening, while 26% said they knew "nothing at all" about it (Durant *et al*, 1996). A more recent study described in the same paper found that 24% of respondents felt they possessed a "clear understanding" of the meaning of the term DNA, while 35% said they had a "general sense" of the term's meaning. When asked to define the term in their own words, only 20% were able to provide a minimally correct definition, while a further 21% made more general references to genes and/or chromosomes.

A German study, also reported in Durant *et al* (1996), found that there was little knowledge about genetic screening but relatively high willingness to undergo testing. In other words, people did not have a clear understanding of the process but thought they would like to be involved, something which could be considered quite alarming to those who believe in informed decision-making.

There were some interesting findings in a recent USA study, which asked the public whether they felt they understood the meaning of "gene" and "human gene

therapy" (Genetics and Public Issues Program, 1998). In contrast to the findings reported by Durant *et al* (1996), 91% of people believed they knew what a gene was, and 49% what gene therapy was. It is possible that the different outcomes between this and the previous studies are due to the fact that this latter study did not determine whether the interviewees' ideas were correct.

It seems apparent then, that the general public are not particularly knowledgeable about general genetics facts. This does not mean they know nothing about the genetics issues which are relevant to them, nor does it preclude them finding information when they personally have a need; it may be that to date, many people have not needed to know.

Of concern were several studies which found that scientific or medical professionals' views of the information most likely to be of use to lay people was often quite different from the public's ideas (Turney, 1995). Such results point to a need for community consultation to determine what people most need and want to know about genetics (Turney, 1995).

Some of the blame for the lack of genetics knowledge and understanding has been laid on the public's ideas of kinship and inheritance (Durant *et al*, 1996; Richards, 1996a; Richards and Ponder, 1996). These are often quite opposite to the commonly held scientific views, and can lead to significant misconceptions, which inhibit accurate understanding of genetic concepts. Examples include the idea that parental traits "blend" in offspring, and that a condition can be gradually "diluted" in severity with each new generation as the "amount" of the disease is spread among the offspring (Richards, 1996a). The conclusions reached by the authors of these papers were based on studies of school children, the public and those who had received genetic counselling. It was felt that in order to overcome the misconceptions, what was termed a "bottom up" approach was required. Traditional approaches have been "top down", where the scientists decided what the public should know, and set about simplifying it in a way they felt would be adequate. The bottom up approach takes into account the previous knowledge and misconceptions existing in the population and tailors education accordingly.

Such a task will not be easy. It has been pointed out that people's ideas come from a lifetime of experience, during which new ideas not fitting past experiences and theories are rejected (Griffiths, 1993). Griffiths (1993, p231) believes patience is necessary. "Students must be taught to be aware of precisely what it is they

believe now and of why they believe it; then there is a chance of showing how the new material is inconsistent with those beliefs."

## The health care professionals

Disease is a health issue, and such issues are dealt with by health care professionals like GPs, nurses and counsellors. The first point of contact for most people affected by a genetic condition will be their local GP, and if he or she does not diagnose the condition or refer the patient elsewhere for testing, it is possible a genetic disease will not be treated in the most efficient way. It is therefore important to ensure these professionals are knowledgeable and up to date with latest developments.

Several studies have identified major gaps in the genetics knowledge of GPs, interns, obstetrician-gynaecologists, psychiatrists and paediatricians, and have called for improved education of these health care providers (Scribanu, Weiss, Kozma, Brown and Panlincsar, 1991; Hofman, Tambor, Chase, Geller, Faden, Holtzman, 1992; Garver *et al*, 1993; Hofman, Tambor, Chase, Geller, Faden and Holtzman, 1993; Boulton and Williamson, 1995; Euroscreen, 1997; Holtzman and Watson, 1997; Kopinsky, 1997; Stephenson, 1997). There was evidence that in one area of the USA, at least, most GPs were aware of and utilised genetics services for their patients (Hayflick, Eiff and Lind, 1995), but this was an exception.

An alarming survey carried out by Boulton and Williamson (1995), measured the knowledge of genetics held by GPs in the United Kingdom. It was found that less than half knew the carrier frequency of CF, a very common illness, and only a third knew the likelihood of producing a carrier child. Despite this, the majority of GPs supported carrier testing, and almost half wanted to offer it in their own practices.

A possible reason for the deficiencies in knowledge is the lack of detailed genetics education at medical schools, and there are calls for universities to rectify this (Hofman *et al*, 1992; Hofman *et al*, 1993; Carrasco, 1996; Holtzman and Watson, 1997; Kopinsky, 1997; Stephenson, 1997). Geneticists themselves have been identified as potential educators of health professionals (Garver *et al*, 1993). The use of the internet to provide information has been suggested, as has the production and distribution of educational CD-ROMs (Stephenson, 1997).

## What has gone before?

This study considers several efforts made across Australia and the world to increase public awareness and understanding about genetic issues. A number of other programs that will not be described in detail have been carried out, and they are briefly described below.

School children have been identified as a good group to educate, and projects have begun to be directed at schools. A teacher training program for elementary, middle and high school teachers was undertaken in the USA, which involved developing educational materials and instructing teachers on how to educate students and their colleagues (Collins and Schimke, 1991). The program resulted in an increase in the number of lessons devoted to human genetics, and in the application of genetics to other subjects, such as maths, social studies and psychology. There was, however, no evidence that awareness had increased within the students, just that more lessons incorporated human genetics. A smaller scale program undertaken during the summer school break taught teachers about human genetics and helped them develop classroom activities (Elbaum, Kessel, Stewart, Owens, Fasking and Patrick, 1992).

In Australia, members of the Victorian Clinical Genetics Service, the Human Genetics Society of Australasia, and the Walter and Eliza Hall Institute of Medical Research provide in-service workshops to refresh and renew teacher knowledge and understanding of genetics and current developments (Victorian Government Department of Human Services, Public Health Division, 1998).

Teaching health care professionals about genetics is another idea that has in recent years been acted upon. A semester-long course called *Incorporation of Genetics into Clinical Practice*, which was aimed at teaching clinicians, educators, social workers and administrators about genetics, was run in the USA (Scribanu *et al* 1991). The participants designed programs aimed at educating others in related fields about genetics and its relevance to clinical practice. The result was that those involved felt more confident in addressing genetic issues, and were often used as information sources by their communities.

Directly addressing the public through high profile channels has the potential to reach large numbers of people, and a group in the USA have tried just this. The Task Force for Public Awareness in New Orleans was formed when new legislation severely restricting access to abortions was introduced. The group felt

the legislation would inhibit responsible decision-making about reproduction, especially with respect to genetic conditions (Rowley, Pelias, Baumbach, Collins, Corson, Davenport, Fleisher, Geller, Harrod, Hogge, Keats, Nussbaum, Orstrer, O'Reilly, Scriver and Speer, 1994). A campaign was organised involving a number of members of the American Society of Human Genetics who spoke publicly at schools, universities, on radio and television, and to newspapers, about genetic services.

Community screening programs for carriers of genetic disorders have been undertaken in the past, and it has been found that success depended on the effectiveness of the educational campaigns accompanying them. An example of a successful program was that undertaken in the Baltimore/Washington region of the USA in 1969 to screen for Tay-Sachs disease, which affects one in 3600 Ashkenazi Jews. Children born with the disease are in a vegetative state by one year of age and die by age two or three. The program was successful both in terms of reducing the number of Tay-Sachs births and informing but not alarming the community. Organisers attributed the success to an "educational process [which] went on long before anyone drew a blood sample" (Roberts, 1990, p18). Community and religious leaders were educated first, and these people then helped educate the public. Testing was aimed at young couples of child-bearing age, a group described as "highly motivated". Collection of blood samples was offered at convenient times, outside business hours, and in locations such as synagogues, store-fronts, and community centres.

In contrast, a program to screen African Americans for sickle cell anaemia, which affects one in 400 of this population, was deemed a failure. The reason for the failure, according to Roberts (1990), was the lack of effort put into education and counselling. The result was confusion and anxiety, and claims of racial discrimination when laws were passed making screening compulsory. These two examples alone provide strong support for the importance of education.

From these descriptions, it is apparent there are many educational efforts currently underway across the world, mostly in the Western countries. In the next three chapters, several programs will be studied in greater detail, and their activities assessed. During the course of the study, it was hoped answers to the research problem and associated questions would be found, thus providing ideas for ways to improve community knowledge of genetic disorders.

# Chapter 3: Programs in NSW

## Introduction

This research is concerned with whether there is information available about genetic conditions and testing, and if it is suited to the needs of the particular audiences who use it.

There are several places one might look for such information. The most obvious and easily accessible of these places are doctor's surgeries and pharmacies, where medical information is traditionally sought. Several of each of these locations were visited, and none provided any information at all. Doctor's surgeries usually have a pamphlet rack somewhere in the waiting room containing brochures on various topics. Of the surgeries visited, most had these racks, but none had any information about HH, genetic diseases or where information might be found. Pharmacies also usually have revolving wire displays or pamphlet racks with medical information – although the pamphlets are most often concerned with medicines and dietary supplements. It was therefore not as likely there would be genetic information at this location, which there was not.

There were no organisations listed in the 'NSW Health' section of the White Pages telephone directory, and nothing in the Yellow Pages. In the alphabetical listings of the White Pages was the "Genetics Education Program of NSW", which was subsequently found to be the major source of information in NSW. While it was listed in the telephone directory, the location of the listing in the residential section may have made it difficult for some people to find. This would be the case especially for those without any prior knowledge of the Program's existence.

Another place information is likely to be sought is the public library. Of two libraries visited, neither had any obvious information about HH. A search of the computerised library catalogue failed to locate anything when a keyword search using "haemochromatosis", "hemochromatosis" (the American spelling) or "genetic diseases" was carried out. When "genetics" was used in a keyword search, about one hundred books were displayed, including the *Genetics Resource*

*Book*, which is published by the NSW Genetics Education Program (GEP). Searching for books with information about HH under the general subject of "diseases" or "medicine" also failed – there were books kept in the libraries but they were outdated and did not contain any mention of HH.

A search of the internet using the terms "haemochromatosis" and "hemochromatosis" resulted in a multitude of useful and seemingly reliable information. There were many internet sites providing detailed and accurate information about the disease, its diagnosis, treatment, genetics, support groups and a number of scientific papers. This is a significant source of information which is very accessible to those who have access to and are proficient in the use the internet. However, it is limited in that many individuals and families do not have access and would not even think of using it. At the time our family was tested, we had no knowledge of the potential use of the internet. A drawback with the use of the internet is that there are no regulations or controls over the information posted at web-sites; it could be completely fictional. The perceived credibility of the information found on the internet is an important consideration in the use of this medium in communicating medical information. Even if information is found on the internet, whether it is coming from a reliable source may be in doubt.

It became clear there are very few readily accessible sources of information in New South Wales, apart from the GEP. As a result, this organisation was the main focus of the study. The type of information produced, whether it is suited to the needs of the target audience, and effectively reaches them, were all considered. A consideration of how the program takes its message to the public was included, and whether improvements could be made in the strategies.

Two other sources of information in NSW, the Association of Genetic Support of Australasia (AGSA) and the NSW Genetics Awareness Week (GAW) were also studied. In addition, another Australian and two overseas projects which aimed to educate or raise awareness were considered (Chapters 4 and 5, respectively). The purpose of this was to compare and contrast their activities with the NSW GEP's, and gain an appreciation of other successful and not-so-successful educational strategies.

# The NSW Genetics Education Program

## About the GEP

Most of the information used in the description of the Genetics Education Program (GEP) came from Dr Kristine Barlow-Stewart, Director of the program.

The GEP began in 1986 with one coordinator working six hours per week. It is based in the Department of Health Promotion and Education at the Royal North Shore Hospital in Sydney. At the time Dr Barlow-Stewart was interviewed in December 1997, the staff consisted of two full-time genetic counsellors, a full-time office manager, and two part-time administrative assistants. Funding is from the NSW Department of Health (Barlow-Stewart, personal communication).

The aims of the program are to provide current and relevant genetics information, as well as promote the access and use of genetics services. Through its activities, the GEP hopes to recognise the effects of genetic conditions and birth defects on individuals and families. The program also seeks to promote the partnership between health, welfare and education professionals who work alongside affected individuals and their families (NSW Genetics Education Program, 1998b).

The GEP attempts to reach an extensive audience. Information is available to individuals and families affected by genetic conditions, professional groups, community service organisations, students, and the general public (NSW Genetics Education Program, 1997). In 1997, 55% of users were health professionals, 20% were individuals and families (including people affected by genetic conditions), 18% were teachers, and 7% of enquiries came from information services or support groups (Barlow-Stewart, personal communication). Individuals and families are usually referred by doctors and other health care professionals, or through newspapers and the internet.

The resources developed and supplied by the program address a variety of areas. Some are concerned with promoting services such as genetic testing and counselling, while others provide information about specific disorders and genetics in general. There is information about peer and family support groups for those affected by genetic conditions, along with updates about recent advances in the diagnosis and treatment of genetic diseases (NSW Genetics Education Program, 1997).

Resources currently available are mostly written, as opposed to video, cassette or multimedia, and are distributed Australia-wide, being used by the education programs of other states (Walpole, Watson, Moore, Goldblatt and Bower, 1997; Victorian Government Department of Human Services, Public Health Division, 1998). Some of the publications are available in 16 languages, and photocopying is encouraged. A detailed list of the resources is found in the Appendix.

The Director and a genetic counsellor compile and write the educational materials they distribute. Fact sheets about specific disorders are updated at least every six months, and frequently an information sheet is prepared on request if a disorder is extremely rare (Barlow-Stewart, personal communication).

Before a fact sheet is released to the public, it goes through rigorous editing and checking procedures. The NSW Genetics Services Advisory Committee (GSAC) Party review and edit all drafts and the final copy, and there is extensive community consultation to determine what has proven effective in the past. The community's cultural beliefs are taken into consideration, and translating documents into other languages is undertaken with care (Barlow-Stewart, personal communication).

Most resources are requested by telephone and a confidential record is kept of clients. The GEP determines specifically the client's needs, and sends that information along with more general information about the program, genetic counselling services and some basic genetics fact sheets (Barlow-Stewart, personal communication). An order form is printed on the back of the GEP information pamphlet, allowing people to request specific information.

In recent years the GEP found it difficult to cope with the huge amount of requests received, and began educating the professionals who were previously referring their patients to the program. Regular in-services and workshops are now run, so that doctors, community health workers and genetic counsellors can meet the needs of their patients without referring them to the GEP. Often it is the genetics unit at the local hospital that runs them, using resources provided by the program (Barlow-Stewart, personal communication). The number of in-services run per year is not known, so it is difficult to say just how many of the state's thousands of health care professionals are reached by these efforts.

Educating at the school level is another of the GEP's goals. Workshops for high school teachers were held in 1997, with the aim of incorporating some teaching

about genetic diseases into the Year 10 science course (Barlow-Stewart, personal communication). There is a student page at the GEP internet site that is intended to assist students with school and university assignments.

In 1997 the GEP had a stand at the Sydney Royal Easter Show, which held information about the program. Visitors were asked to complete a survey about their attitudes towards and understanding of genetics, with a pair of jeans offered as a prize. The survey was completed by 4,500 people over the course of the ten day long Show. Dr Barlow-Stewart, reported that there were queues to fill in the survey, particularly on Senior Citizens day. It was her belief that 80% of the respondents were answering the survey out of interest rather than the desire to win the prize. Perhaps surprisingly, given the generally low level of genetics knowledge reported in the literature (Griffiths, 1993; Harper, 1992; Kerr, 1996; Olopade, 1996; Richards, 1996a; Richards and Ponder, 1996; Williamson *et al*, 1989), the average participant knew the answers to most of the questions in the survey (Barlow-Stewart, personal communication).

The GEP have in the past been involved in Genetics Awareness Week in NSW, working with the Association of Genetic Support of Australasia (AGSA) to promote awareness of hereditary conditions to the general and affected public. The 1997 Genetics Awareness Week, with which they were involved, is described later in the chapter.

The GEP provides assistance to the media, with "sensitive and accurate" media coverage viewed as valuable. The *Genetics Resource Book* is provided free of charge to science journalists. It is Dr Barlow-Stewart's belief that the GEP is now the first place journalists look for information about genetic diseases, with the program viewed as a credible and reliable source of information. The GEP in many cases refers the journalist to a specialist, or if it is an affected family sought, helps facilitate contact with a family willing to participate in stories. When seeking publicity for an event such as Genetics Awareness Week, both the GEP and AGSA prepare and distribute media releases and assist in the preparation of stories. Advertising in newspapers was not seen to be particularly effective, so it is generally not undertaken (Barlow-Stewart, personal communication).

At the time of interviewing, Dr Barlow-Stewart was conducting the GEP's second mail-out in ten years. Brochures and information sheets were sent to GPs across the state. Such a project was seen as too expensive to warrant undertaking more regularly (Barlow-Stewart, personal communication).

The GEP favours the use of interactive education, drawing people in by showing them how genetics is relevant to them personally. Consideration is given to what has worked in the past when designing material (Barlow-Stewart, personal communication). People affected by a condition will already have an interest, but others are reached by the use of such activities as the *Do you know your genes?* family health tree exercise. This exercise encourages people to delve into their family health history in order to identify any hereditary conditions that might be present.

Measuring the success of the GEP's activities is not simple. The promotion of genetics awareness and understanding is not like advertising goods and services, where success can be measured by the amount of units sold. Just how many people the GEP reaches cannot even be measured by calculating the amount of pamphlets distributed, books sold, or people at events. Measuring the readership of pamphlets and books is impossible because photocopying is so common. The number of visitors to the internet page can be measured but cannot give a guarantee that the visitors found what they were looking for, nor that they did not download the information and distribute it.

The GEP evaluates its activities in a number of ways. A client record system is kept which is used to evaluate requests, referrals and actions that are taken by the program. The *Genetics Resource Book* is evaluated by the distribution of surveys, which has led to some changes over the various editions. Teachers and clinical genetics units have reported that the GEP is invaluable to them, with the genetics units using the service's resources daily. Evaluations and reports are prepared annually and each November there is a planning period for the following year (Barlow-Stewart, personal communication).

In 1998, the program's focus was reaching different ethnic groups, looking at what information the groups needed and how best to reach them. Specific community groups were targeted, with the translation of some pamphlets into different languages and onto cassette (Barlow-Stewart, personal communication).

A summary of the GEP's main efforts to reach the community is given in Table 1. More detailed descriptions of two of the efforts, the *Genetics Resource Book* and the GEP internet site, follow.

| Project | Audience |
|---|---|
| *Genetics Resource Book* | The interested public (affected families and health care professionals), the general public (the media) |
| Internet site | The interested public, the general public |
| Royal Easter Show stand | The general public |
| In-services and seminars | The interested public (health care professionals) |
| Teacher education projects | The general public (teachers and students) |
| Media liaison | The general public (the media) |
| Genetics Awareness Week* | The general public, the interested public |

**Table 1: The NSW Genetic Education Program's main efforts to disseminate information.** The fact sheets are not included as they are specifically requested by the public or health care professionals.
* see later in this chapter for a description of the event

## The *Genetics Resource Book - The Australian & New Zealand 1998/1999 Directory of Genetics Support Groups, Services and Information*

One of the main resources produced and distributed by the GEP is the *Genetics Resource Book* (NSW Genetics Education Program, 1998a). It is updated annually, and is endorsed by the Human Genetics Society of Australasia, AGSA and Parent to Parent, New Zealand, all of whom contributed to its production. The book is produced by the NSW GEP but has details of services and contacts across Australia and New Zealand, making it suitable for distribution in all these areas.

Most users of the *Genetics Resource Book* find out about it by mail-outs, word of mouth, seminars and newsletters. The first edition of the book was distributed eight years ago, so it is now well known, according to Dr Barlow-Stewart. Libraries and schools are directly approached by mail-outs, but there is no paid advertising of the book. From the end of April to mid-July 1998, 350 copies of the update to previous editions had been purchased and almost 250 copies of the new *Genetics Resource Book*. The main purchasers of the book were (from most to

least purchased) health care professionals, community centres, schools, hospitals and libraries (Barlow-Stewart, personal communication). The cost depends on the version purchased, with the bound, soft cover edition costing $30, the loose-leaf binder version for $40, and the loose-leaf update for $25.

The first section of the *Genetics Resource Book* contains general information about genetic disorders and has the details of over one hundred genetic or suspected genetic disorders. Included are the contact details of support groups across Australia and New Zealand.

Section Two describes genetics services in Australia and New Zealand, what they are and how they can be accessed. These include genetic counselling, clinical genetics services, laboratory services, and education and health promotion programs.

Making up just under half of the book, the third section provides a variety of information about genetics and genetic diseases. It begins with the *Do you know your genes? A Guide to drawing a family health tree* exercise, mentioned above. Thirty-seven fact sheets follow, as well as a *Glossary of genetic terms*, a page of *Selected references in genetics*, and a list of *Publications and audiovisual references in genetics*.

**Analysis of the *Genetics Resource Book***

The main audience of the book are the affected public, either directly or via the health care professionals who work with them. The *Genetics Resource Book* is used to a lesser extent by the general public, mainly through the media and school teaching. Realistically, the general public is likely to have little or no interest in reading such a publication. Evidence for this is provided by the lack of private purchasers, as reported by Dr Barlow-Stewart.

It is the GEP's aim to distribute the book widely, in libraries, to health care professionals, schools and the general public, but information about the 1998/99 edition has so far only been disseminated among those who purchased the previous edition. The advertisement of the book should probably be extended more widely than simply to those who already possess a copy, and could include more community centres and hospitals.

The *Genetics Resource Book* aims to educate those specifically seeking information rather than raise awareness. It is a resource that will be sought out by those in need, not one that draws attention to itself. A person not affected by a genetic condition, or with no interest, will not be aware of the existence of the book. It is highly useful to those who need it, but is unlikely to be of interest to those who do not. The audience is a specialised one, and the book itself is tailored to the needs of the health care professionals who have to inform their patients, and to the needs of the patients and families struggling to understand a complex issue.

The book has its advantages for the GEP. Since it contains a great deal of information, and can be photocopied, the needs of many people can be met by the book without any contact with the program itself.

## The GEP internet site (www.genetics.com.au)

A useful resource for those with access to the internet, the GEP site provides information about the program, details of where to find clinical genetics services and support groups, a list of available resources, and a student page (NSW Genetics Education Program, 1998b). Essentially, it is a quick overview of the program, giving the user an idea of what the GEP has to offer. During the month of March 1998, 137 people visited the GEP home page, while there were 35 recorded visits to the student page (Barlow-Stewart, personal communication).

There is a page about clinical genetics services in NSW, and a list of genetic disorders about which fact sheets are available upon request. The student page has links to internet sites devoted to some of the more common genetic disorders, as well as general reference lists. A recent addition to the site is a survey about the ethics of genetic testing, and what people's obligations to their family, employers and insurers are. The resources available through the program are listed, with information on how they can be requested. Finally, there is a *What's on* page, with details of current GEP projects. Of interest are two papers underway at the time of this study, one reviewing the activities of the GEP, the other analysing thirteen years of public knowledge and attitudes in genetics. Unfortunately at the time of writing this sub-thesis they could not be obtained.

### Analysis of the internet site

The internet site is a good initiative, given the increasing popularity and use of the internet by families, schools and businesses. It is more effective at raising awareness than educating, due to the lack of detailed genetics information. It is most likely to be used by those affected by genetic conditions, or students seeking information for assignments, as the general public probably have no interest.

One advantage is that the potential audience is large and widely distributed. The GEP page can be viewed by anyone with access to the internet. If some of the less sensitive information posted and faxed to people by the GEP was placed on the internet, the program could reach many more people, and without requiring the time of the GEP staff. Only a small amount of time searching the internet would uncover many more relevant sites, to which links could be made from the GEP page. Links could also be provided to clinical genetics services or support group sites, including the AGSA home page.

Finances permitting, the page could also incorporate interactivity, such as the current quiz or multimedia programs designed to teach about genetics. This is a definite advantage over conventional, printed information.

A drawback to this approach is that not all people have access to the internet, particularly families with a sick child who might be struggling financially. These people would need to access GEP information in the traditional manner. The site itself needs to be sought out so it is not a valuable tool in raising awareness in those who do not look for it.

## Analysis of the GEP as a whole

The GEP is an organisation that produces a great deal of genetics information, most of it for the affected public, the health care professionals, the media and students. Information about services, genetic conditions, and support groups is provided. Some ethical issues are considered, and updates are provided about disease diagnosis and treatment. Table 2, on page 27, gives a summary of the main audiences, aims, advantages, disadvantages and suggested improvements to the projects undertaken by the GEP.

There are several aspects of the program worth considering. Firstly, the advertising of the service. To reach affected families, advertising will be most

effective when directed at the health care professionals, who are in the best position to disseminate information to these people. Almost all those affected by a genetic condition will come into contact with a health care professional in the course of their diagnosis or treatment.

If my family's GP was better informed we could have received information quickly and without hassle. Even if the health care professionals do not learn anything from the program themselves (although it is hoped they would), simply knowing about its existence means they can refer patients in need to the GEP. The mail-out to GPs, while being expensive, is a useful exercise. Other means of advertising, such as in medical bulletins, could also be undertaken. Perhaps doctors could be informed of the program while they are studying for their degree, as part of an assignment or their clinical practice.

Educating the doctors and health care professionals is one of the GEP's activities, through in-services and training programs. Whether these are reaching a substantial proportion of the state's medical professionals is not known, but they should definitely be continued and if possible scaled up. There are other strategies that could also be considered, such as seminars featuring prominent speakers in research areas of relevance. Workshops and in-services are good for professionals who can take the time off, but busy GPs may find an hour spent occasionally at a seminar more convenient. Having the workshops recognised as part of GPs' ongoing professional education so that the doctors receive benefits for participating may be another way of increasing attendance.

There are a number of resources produced for use by the general and interested public, but most of these are written. It is possible that many people understand and respond to information better if it is presented in a visual, perhaps interactive, form. Fact sheets and books may lose the interest of a number of readers. An up-to-date video library could be a useful resource, as could interactive multimedia programs aimed at various audiences. School children may have access to computers that can run CD-ROMs, and this may be an engaging and stimulating way of presenting genetics concepts.

Apart from the GAW, Royal Easter Show stand, and media support, the GEP does not invest much of its time in promoting genetics awareness within the general community. More could be done to raise awareness about hereditary diseases within the general public. It is usually for their own benefit that currently unaffected individuals are made aware of possible risks associated with a family

history of genetic illness. In my family, it may have saved lives had we identified family members who were carrying the mutant HH gene. How the GEP might go about raising genetics awareness is discussed below and Chapter 6.

The GEP is involved in educating at the school level, to help keep teachers up to date about genetics. It is beneficial for students, as they learn about genetics while they are young, before any significant misconceptions can arise. The teacher education undertaken by the GEP only involved eighty teachers in 1997 (Barlow-Stewart, personal communication), an insignificant number compared to the overall population. This could be improved by running in-services that instruct teachers how to develop their own educational materials, and how to educate their colleagues.

A teaching kit could be sent out annually, providing information about genetics and any developments in the field of medical genetics. Photocopying and distributing it statewide would be quite expensive, however sending it electronically, via the internet or e-mail could cut down expenses. Kits could be developed for children of different age groups, designed with the school science curriculum in mind. Interactive teaching programs could be placed at the GEP internet site rather than distributed via CD-ROM, for students to use at home or at school. Such initiatives are likely to be quite costly, and their implementation/development would be limited by the GEP's finances.

The stand at the Sydney Royal Easter Show had the potential to reach a wide audience in an informal environment, and from Dr Barlow-Stewart's account, there was an enthusiastic response to it. Surveying genetics knowledge may be useful for the GEP but whether many people left the stand knowing any more about genetics, or even where the GEP is located, could be questioned. Interactive displays that conveyed some information about genetic diseases would probably have been worthwhile.

The GEP assists the media in the production of stories, which will improve the quality and quantity of stories, and reach a wide audience. The only danger with this effort is that information could be taken out of context or misrepresented, with potentially damaging effects. More could be done to utilise the media, such as presenting entertaining speakers on highly rating television or radio shows.

Science centres are other outlets for genetics information. Interactive and informative genetics exhibits could be devised and produced. This could be done

by the GEP in collaboration with a science centre (such as the Powerhouse Museum in Sydney). With the exhibit could be information about the GEP and further sources of information. Some corporate sponsorship could be sought to cover cost and assist with development. The International Centre for Life at Newcastle in England is an example of a science centre that will house interactive genetics displays (The Wellcome Trust, 1998). Displays on a slightly smaller scale could be carried out in Australia, using similar ideas to the British centre.

On the whole, the GEP produces a variety of information, most of it designed and distributed with affected families and health care professionals in mind. The general public does not receive a great deal of information, although the GEP undertakes some small scale initiatives such as media support and teacher education which could make a small contribution to raising public knowledge. This aspect of the program's work will be discussed further in Chapter 6.

| | The Genetics Education Program and its main strategies |
|---|---|
| **Audience** | Those affected by genetic conditions or considering testing, the general public, the media, students, health care professionals |
| **Aims** | Educate and raise awareness about genetic conditions, services and support groups<br>Promote tolerance and understanding<br>Update on developments in research<br>Promote discussion of ethical issues |
| **Advantages** | Coordinated organisation focussing on most aspects of genetics education |
| **Disadvantages** | Some resources not as well developed as they could be |
| **Improvements** | Many individual areas, finances permitting, as described below |
| | **The *Genetics Resource Book*** |
| **Audience** | Those affected by genetic conditions or considering testing, the media, students, health care professionals |
| **Aims** | Educate and raise awareness about genetic conditions, services and support groups<br>Update on developments in research<br>Promote discussion of ethical issues |
| **Advantages** | A large variety of information provided<br>Can be readily photocopied and distributed<br>Reduces workload for GEP once book is available - many queries answered by it<br>Details of further sources of information |
| **Disadvantages** | A static form of education - it must be read<br>Education is passive rather than active - the book must be sought out<br>Reader must already be interested to want to pick the book up, use is limited by its distribution |
| **Improvements** | Advertise and distribute widely |

**Table 2: An analysis of the main methods used by the NSW Genetics Education Program to distribute information**

| | The main strategies used by the NSW Genetics Education Program |
|---|---|
| | **Internet site** |
| **Audience** | All of the audiences identified for the program |
| **Aims** | Raise awareness of the Program, genetic conditions, services and support groups<br>Promote discussion of ethical issues |
| **Advantages** | Potentially a very wide audience<br>Easily accessible for those with internet access<br>Some maintenance required by GEP but reduces workload in terms of direct enquiries<br>Has potential for effective dissemination of a large amount of information<br>Can incorporate interactivity |
| **Disadvantages** | Only reaches those with internet access |
| **Improvements** | More information<br>Interactivity<br>More links to other genetics pages |
| | **Teacher education projects** |
| **Audience** | Teachers and students |
| **Aims** | Begin genetics education young, by teaching children. Improve teaching, make it more up-to-date |
| **Advantages** | Children learn early, before significant misconceptions can arise<br>Education of one teacher can result in increased knowledge of many more children |
| **Disadvantages** | Only a small number of teachers attend in-services |
| **Improvements** | Send out teaching kits to schools, developed with science curricula in mind<br>Run seminars designed so that teachers can develop their own educational materials and help other teachers do the same |

**Table 2 continued: An analysis of the main methods used by the NSW Genetics Education Program to distribute information**

| | The main strategies used by the NSW Genetics Education Program |
|---|---|
| | **Media liaison** |
| **Audience** | The media and the general public |
| **Aims** | Provide accurate information for journalists<br>Promote awareness of genetic conditions and services |
| **Advantages** | Better awareness within media circles<br>More accurate and sensitive stories |
| **Disadvantages** | Information could be taken out of context or misinterpreted |
| **Improvements** | High profile speakers on highly rating shows and in newspapers could raise interest in genetics |
| | **Royal Easter Show stand** |
| **Audience** | The general public |
| **Aims** | Raise awareness of the program, services and genetic conditions<br>Survey genetics knowledge |
| **Advantages** | Potentially a very large, diverse audience<br>Opportunity to hand out information and talk to people in an informal, leisure environment |
| **Disadvantages** | Many people visiting these stands are just looking for free rulers! |
| **Improvements** | Incorporate interactive activities into the stand e.g. computer programs. |

**Table 2 continued: An analysis of the main methods used by the NSW Genetics Education Program to distribute information**

| | The main strategies used by the NSW Genetics Education Program |
|---|---|
| | **Seminars for health care professionals** |
| **Audience** | Health care professionals |
| **Aims** | Improve knowledge about genetics conditions<br>Improve awareness of services and the GEP<br>Update about relevant technology |
| **Advantages** | Information tailored to their needs<br>Information delivered visually<br>Can interact with person delivering information |
| **Disadvantages** | Only reach those in the audience<br>Could be difficult for busy staff to get time off work |
| **Improvements** | Videos<br>Train professionals to deliver seminars to their colleagues |

**Table 2 continued: An analysis of the main methods used by the NSW Genetics Education Program to distribute information**

# The Association of Genetic Support of Australasia (AGSA)

## About AGSA

Most of the information contained in this section came from an interview with Ms Dianne Petrie, Support and Education Officer of AGSA.

Formed in 1988, the Association of Genetic Support of Australasia is funded by the NSW Health Department, and is located at Surry Hills in Sydney. A committee of twelve people, including genetic counsellors, clinical geneticists and affected families is responsible for overseeing AGSA's operations. The Support and Education Officer, Ms Dianne Petrie, coordinates activities and is the point of contact for most people. AGSA is not attached to any major educational or health care institute, giving it autonomy and an independent voice (Petrie, personal communication).

AGSA's main aim is to provide support for people affected by genetic conditions. This is achieved by acting as an umbrella organisation for the many genetics support groups across Australia and New Zealand. Families contact AGSA, and are given details of where they can locate support groups or other people in a similar situation. These people can offer support to each other and share knowledge and resources. If there is no support group, AGSA often helps set one up. Support group meetings are held at AGSA, as well as full day seminars, which are attended by affected families and relevant health care professionals who provide updates and information (Petrie, personal communication).

Members of AGSA run seminars across Australia, speak at conferences and universities, and organise exhibits at fairs and shows. A bimonthly newsletter is distributed, as well as a variety of pamphlets and brochures, including many from individual support groups (Petrie, personal communication). Much of the focus is on raising awareness of support groups and AGSA itself, and providing information about where help can be found. Their main concern is not with educating *per se*, as the NSW GEP already fulfils this role. The two organisations cooperate to provide services that are non-overlapping. AGSA organises annual Genetics Awareness Weeks (GAW), one of which is discussed later in this chapter. This event is directed at and attended by affected families, the health care professionals and to a lesser extent, the general public.

The office in Surry Hills receives over 100 telephone calls per month, between the hours of 10am and 2pm Monday to Friday. About half of these are health professionals, while the other half are affected families. People find out about AGSA in a number of ways: from the GEP, genetic counsellors and clinical geneticists, GPs, and by word of mouth (Petrie, personal communication).

Others see advertisements and newspaper stories about AGSA. The program does not pay for advertisements, but some magazines will include them free of charge if there is space available. Media releases are distributed, which include a story written by AGSA and the contact details of families who are willing to be interviewed. Popular magazines have in the past run stories about prenatal testing and inherited conditions in general, including interviews with Ms Petrie of AGSA, and Dr Barlow-Stewart, Director of the NSW GEP. Pamphlets are not distributed to general medical practices, as Ms Petrie believes there is a good chance the material will simply be thrown away (Petrie, personal communication).

Helping people make informed decisions is something which was suggested in Chapter 2 as being an important goal of education and awareness programs. For couples deciding whether to abort a foetus affected by a genetic condition, information about the genetics and medical implications is not enough. There are emotional issues to be considered. AGSA helps by putting people in this situation in contact with support groups or families who have been in the same position and can pass on their experience (Petrie, personal communication). AGSA is not biased towards aborting or continuing a pregnancy, being interested only in helping people make decisions which are right for them.

An internet site has been set up, at www.span.com.au/agsa/index.html. It is a small site, taking only two A4 pages to print out. It contains similar information to the AGSA pamphlets, including a general description of genetic conditions, figures for the number of people affected by genetic conditions, and details of how AGSA facilitates contact with support groups and families. Contact details for AGSA and two support groups are included, and details of events for 1997. The absence of events for 1998 when the page was sourced in June 1998 suggested that the page had not been updated for some time. There was no indication as to when the site was last updated.

A brief summary of AGSA's main activities is given below in Table 3.

| Project | Audience |
|---|---|
| Internet site | Interested public, general public |
| Seminars and workshops | Interested public, general public |
| Talks at conferences and universities | Interested public, general public (students, the media) |
| Exhibits at fairs and shows | General public, interested public |

**Table 3: The ways AGSA takes its message to the community**

## Analysis

AGSA's main aim is to provide support for those affected by genetic conditions. They do not attempt to reach the general public to the same extent as the GEP, but do try to raise awareness of the existence of the organisation. Their efforts are mostly directed at providing information and support to those affected by genetic conditions. Table 4 on page 34 gives an overview of the main aspects of AGSA's activities and suggested improvements.

The main improvement AGSA could make would be to improve knowledge of the organisation within the medical community. This would ensure that when an affected individual or family needed support, they would be referred to AGSA. Sending brochures to GPs may in fact be a useful effort, despite Ms Petrie's belief that they may be thrown away.

| | Association of Genetic Support of Australasia |
|---|---|
| **Audience** | Individuals and families affected by genetic disorders, health care professionals |
| **Aims** | Educate and raise awareness about genetic issues, particularly support groups and services<br>Provide updates and support for affected families<br>Assist people in making informed decisions |
| **Advantages** | A lot of support provided for those affected by genetic conditions |
| **Disadvantages** | Short office hours |
| **Improvements** | More effort to advertise service to health care professionals |

**Table 4: A summary of the activities of the Association of Genetic Support of Australia**

# Genetics Awareness Week 1997

## About Genetics Awareness Week

Genetics Awareness Week (GAW) is an annual week aimed at raising awareness of genetics and its effect on individuals, families and society. In the past, it has been run solely by AGSA, with the exception of 1993, when the NSW GEP assisted. In 1997, the GEP were again involved. Activities were held across NSW (Barlow-Stewart, personal communication), but this description will focus on a series of public forums on genetics held at the Powerhouse Museum in Sydney. Most of the information contained in this section was obtained from attendance at the event and information collected during the weekend. Dr Kristine Barlow-Stewart, Director of the GEP, and Ms Dianne Petrie from AGSA, also provided information. The seminars at the Museum will be referred to as the GAW, although it was not the only component of the state-wide Week.

The 1997 GAW was launched at the Powerhouse Museum with a private function for professionals, staff, support groups and families. The evening was not advertised to the general public. It featured brief talks from Ms Dianne Petrie and Dr Kristine Barlow-Stewart, of AGSA and the NSW GEP, respectively, as well as two members of the New Children's Hospital at Westmead, and three people living with a genetic condition. The talks were concerned with the interaction between genetic support groups and health professionals, and what people with a genetic condition had achieved.

The following weekend saw the public launch of GAW at the Powerhouse Museum with free lectures on the theme *Do you know your genes....or do you want to?* The first lecture was entitled *Genes and cancer: What's the link?*, and was given by the Dr Kathy Tucker, head of the Familial Cancer Clinic, and Ms Margaret Gleeson, an Associate Genetic Counsellor at the Prince of Wales Hospital in Sydney. Following this was a talk called *Solving crime with DNA*, presented by Dr Brian McDonald, Managing Director of DNALABS Sydney IVF, at Camperdown in Sydney.

On Sunday there were again two sessions, the first one featuring two speakers, on the topic of *Treatments for genetic disorders - today and tomorrow.* Dr John Christadoulou, Program Director of the Western Sydney Genetics Service at the New Children's Hospital in Westmead delivered a lecture concerning *Genetic*

*disorders - treatments today*. He was followed by Dr Ian Alexander, Head of the Gene Therapy Unit at the New Children's Hospital, whose talk was titled *Gene therapy - a new medicine?* The final lecture in the series was concerned with genetic testing and insurance.

Most of the public lectures could be easily understood by a person with a non-scientific background. The gene therapy speaker had succumbed to the urge of putting in scientific pictures (such as cells with reporter genes being expressed and detected) which would have made no sense to anyone except scientists, but directed his talk at the correct level.

In the foyer outside the theatre were several displays by a variety of scientific organisations, including a DNA testing laboratory. None of the displays had any interactivity, although several were operating pieces of lab equipment, including one who had their electrical cords plugged in with the wrong polarities, so their experiment, which was separating DNA fragments on the basis of size using electricity, was running backwards. There was a genetic counsellor available, and some tables with pamphlet displays, including one from AGSA.

There was a hands-on DNA extraction workshop run by CSIRO's Double Helix science program, aimed primarily at school children. Interestingly, at the session a friend and I attended there were more adults than there were children.

The NSW GEP set up two touchscreen computer displays with surveys in which visitors could participate. These were concerned with ethical issues and were very similar to those found on the GEP internet page. Dr Barlow-Stewart, Director of the NSW GEP, reported that 300 surveys were completed over the two days, which she felt was a good response given the length of the survey, which was considerable. This figure only included those who filled in all of the three questions, so many more may have completed one or two questions.

About one quarter of the theatre was filled for most sessions, making the audience at each session about sixty people. Dr Barlow-Stewart felt the weekend was a success, despite it being difficult to measure what people gained from attending.

The seminars were advertised the previous week in the Sydney Morning Herald, one of Sydney's major newspapers. Media releases were sent out well before the event, resulting in coverage by the larger Sydney newspapers and the Cumberland

newspaper group, which publishes on a smaller scale within individual districts (Petrie, personal communication).

Table 5, on page 40, gives a summary of the main activities of the GAW, their advantages, disadvantages, and where improvements could be made.

## Analysis

The GAW was not aimed at one audience in particular, as evidenced by the choice of general genetics topics and the title of the seminar series (*Do you know your genes...or do you want to?).* Only one seminar, on familial cancer, was aimed at a specific audience. The general public, those without a direct interest in the seminar topics, are unlikely to have been sufficiently interested in the topics to go out of their way to attend any of the lectures. The seminars were therefore unlikely to have been successful in raising genetics awareness within the general community.

If the general public are eliminated from the potential audience, it leaves the interested public. Health care professionals may have attended and so might affected individuals and families. Whether they did or not depends on a number of factors.

Having seminars in a fixed location meant that the audience had to go out of their way to receive the information, rather than the information coming to them. This is likely to be a significant deterrent to many people, especially affected families with sick members.

The use of the Powerhouse Museum as a venue may or may not have been an advantage. On the one hand, it is located centrally in Sydney, close to public transport and parking. On the other hand, travelling into the city can be a problem, especially for families and those who live in the outer suburbs. A series of lectures given at various locations around Sydney and nearby regional areas might have reached a greater number of people, even if there was a smaller attendance at each venue. Whether this was a part of the activities held in other areas is not known. If it was not, it certainly should have been considered as an alternative to the one-off lecture series in central Sydney. The cost to enter the Museum may also have been a deterrent - it was about $8 per adult at the time, a cost some may have been unwilling to pay for a one hour lecture.

The genetics of familial cancer is a popular topic and one that is quite frequently in the news. There exist considerable misconceptions such as whether a daughter will "get cancer" if her mother has breast cancer. It was of note that the speakers paid attention to this point, emphasising that not all forms of cancer are inherited, that just because one's parent had cancer does not mean they themselves will develop it, and that even if a person undergoes genetic testing and finds they carry a gene predisposing to cancer, this does not definitely mean cancer will develop.

Attendance could have been greater, and perhaps this might have been achieved by more advertising. The 1993 GAW was advertised very widely, with banners appearing on bridges and other prominent places (Barlow-Stewart, personal communication). Information about GAW could have been included in a media release about a research development, which might have increased media coverage of the event.

It seems unlikely that a lecture series was the best way to raise awareness among those who do not already have an interest in genetic conditions. Television, radio, or newspaper specials might have reached a larger audience and attracted more interest. Features for the specialty radio or television science programs could have been organised, or the assistance of a television network enlisted. A network could have run a number of pre-existing genetics programs over the course of a week, such as those by David Suzuki. The appearance of speakers on radio talk shows or television current affairs, midday lunch, or general entertainment programs such as *Good News Week* would have reached a larger audience. The depth of information conveyed might not have been as great, but in combination with a similar lecture series, and some informative programs, the interest of the general public might have been gained. Having made these suggestions, it may be that the organisers had neither the time nor finances to undertake such a large-scale effort.

Having a central venue did give the opportunity for the presentation of displays and the workshop. These gave the visitor the opportunity to witness and take part in laboratory experiments, and speak to trained staff immediately if there were any questions. It also allowed for the display of further information, which could be taken away if desired. One drawback of the displays was that they were mostly static, with very little interactivity. There were not a great deal of them, either,

which meant there was not much variety. A simple solution would be to increase the number of stalls, and encourage exhibitors to be more creative with their displays.

| | Genetics Awareness Week 1997 and its main components |
|---|---|
| **Audience** | The affected public, the general public |
| **Aims** | Raise awareness of genetics issues and services |
| **Advantages** | Potential to reach a wide audience |
| **Disadvantages** | Audience could have been greater, and likely to be mostly the affected public<br>One-off lecture series and central location could have put some people off attending |
| **Improvements** | More advertising of the event<br>More displays in the foyer<br>Other venues<br>Utilisation of the media such as television and radio |
| | **Public seminars** |
| **Audience** | As above |
| **Aims** | As above<br>Provide updates and dispel some myths about genetics |
| **Advantages** | Topics of general interest to a potentially large and varied audience<br>Central location in the middle of Sydney |
| **Disadvantages** | Venue might have been difficult to get to for some, especially those with families<br>Seminars were one-off, so people had to be able to make it to that location on that day<br>General public probably not likely to attend |
| **Improvements** | Deliver seminars at more than one location<br>Advertise more widely, and find a news peg |

**Table 5: The main components of the 1997 Genetics Awareness Week**

| | Genetics Awareness Week 1997 and its main components |
|---|---|
| | **Displays/workshops in foyer** |
| **Audience** | As above |
| **Aims** | As above |
| **Advantages** | Visitors peruse at their own speed and what they choose<br>Potential for interactive, hands-on displays<br>Information to take away<br>Children can take part in scientific experiments<br>Can talk to trained staff |
| **Disadvantages** | No interactivity used except computers which were running a survey<br>Need a lot of displays to make it impressive |
| **Improvements** | A greater number of interesting displays<br>Equipment at scientific stands run correctly |

**Table 5 continued: The main components of the 1997 Genetics Awareness Week**

# Chapter 4: other Australian projects

## The Hereditary Disease Project

### About the project

The Hereditary Disease Project (HDP) was undertaken jointly by the Genetic Services of Western Australia, the Faculty of Health and Behavioural Science at the University of Wollongong in NSW, the Hereditary Disease Program of the Health Department of WA, and the Birth Defects Registry in WA. It was designed to test out some simple, low-cost approaches to increasing knowledge and awareness of hereditary disease within a community.

The project was reported in the *Journal of Medical Genetics* by Walpole, Watson, Moore, Goldblatt and Bower (1997). It was carried out over eighteen months during 1992 and 1993, and targeted five adjacent postcode areas of metropolitan Perth, Western Australia, with a total population of 51,000. Before the project began, 250 interviews with the general public were carried out to assess community knowledge about hereditary disease.

A similar number of interviews were conducted after the project finished, in an attempt to measure the increase in knowledge. For both surveys, random members of the community were questioned for 15 minutes in a shopping centre by trained interviewers. They were asked about genetic conditions and testing, and whether they knew where to obtain information about hereditary disease. Information about these issues was contained in the material distributed to public places and directly into mailboxes of each household during the project.

Promotional materials were developed for the project, and included pamphlets about genetic counselling, constructing a family health tree, hereditary diseases, and prenatal tests for birth defects. Two posters were produced: *Will my baby be born healthy?,* and *Check your family tree.* Pamphlets and posters were distributed to all GPs, as well as child health nurses (CHNs), pharmacies, households, shopping centres, health fairs, the media, libraries, child health centres, day care centres, and kindergartens. Kits with details about the project and general information about hereditary diseases were given to health care professionals and the media. A bimonthly newsletter about the project was sent to

GPs, meetings and seminars were held with GPs and CHNs, and a static display entitled *Will my baby be born healthy?* was set up in various public locations.

Newspapers were used to promote the project. Over a three week period, the local community newspapers included stories about hereditary diseases and there were three full-page advertisements on the *Will my baby be born healthy?* theme.

Over the course of the project, all households in the target area received a direct letterbox drop. Included was a leaflet *What do you know about hereditary diseases?/Know your family tree*, as well as a questionnaire and return mail card with two multiple choice questions. One of these related to the meaning of the term "genetic disease", while the other was concerned with the chance that a baby born in Western Australia has a birth defect. The response rates when incentives (the chance to win a pair of jeans, or receive more information about hereditary diseases) were offered were compared with those when no incentive was offered. Response rates averaged 3%, with no consistent differences when there were incentives to reply.

A phone line and answering service was set up to receive requests for information. Genetic outreach clinics were established within child health centres, to provide specialist genetic information and deal with referrals from local GPs, CHNs and from the community themselves.

## Outcomes

The project was divided into two parts - reaching the health care professionals and the general community. Success with the general community was measured by the pre- and post-test surveys, response rates to the material delivered to mailboxes, and use of the genetics outreach clinic and other services. Whether the project reached the health professionals was determined by surveys posted to GPs, referrals to genetics services, and the attendance of CHNs at professional seminars and in-services.

### The health care professionals

The surveys posted to GPs at the conclusion of the eighteen months asked them to comment on the importance of projects like the HDP in community education. Most GPs demonstrated support for the initiative, and felt it was of value. The majority could see a role for GPs in managing patients with hereditary disease,

and said they would continue to display posters and pamphlets. They thought they would continue to refer patients to genetic counsellors and for testing. CHNs were similarly enthusiastic and cooperative, attending seminars and referring patients to the genetics outreach clinic, which was fully booked by the end of the project. This aspect of the project was a success, as health professionals were more aware of the importance of genetics in general health and were more likely to refer patients to genetics services as a result of the project.

**The general community**

The general public was not as receptive as the health care workers, according to the authors of the study. The post-test survey revealed there was little increase in knowledge about hereditary disease as a result of the project. Not much was known about genetics, either before or after the HDP. Those most likely to answer the survey questions correctly were those who were married, middle aged, had children, had a higher level of education, or were born in Australia, New Zealand or the United Kingdom. More females than males could name a genetic condition. There was no improvement in knowledge about who might benefit from genetic counselling, although there were changes in the public's perceived sources of information, with health professionals, hospitals and the Health Department nominated more frequently after the project ended. Fewer than one in four respondents knew that genetic counselling services existed, and there was little increase in this knowledge after eighteen months of the project.

Respondents were asked in the second survey whether they had seen the pamphlets and posters produced for the project. Only 8% of males, and 17% of females had seen the pamphlets, and 11% of males and 38% of females had seen the most widely distributed of the posters. Despite the mail-outs to every household in the area, only 14% of males and 21% of females recalled receiving anything about hereditary disease in the post. An interesting though not surprising finding was that those who had seen the pamphlets or posters were about three times more likely to choose the correct definition of a genetic disease.

Walpole *et al* reached several conclusions regarding the approach they had taken. Despite their efforts, there were few significant improvements in knowledge, and the overall level of knowledge was not high. A few possibilities for why the project was not able to improve awareness were suggested, including the notion that the time frame of the project was too short, and that recipients were unable to comprehend such complex information in such a short time. That the information

was not distributed widely enough was another possibility, despite the fact that the materials were displayed in many places women and children congregated, and that every household had received information about the project.

The authors felt that perhaps the materials needed to be more diverse, and contain messages with greater relevance to the informal or lay views of the community. Lay beliefs can have a significant impact on the uptake and understanding of hereditary disease, due in part to the tendency of the new information to be against people's intuitive ideas about the topic (Durant *et al*, 1996; Richards, 1996a; Richards and Ponder, 1996).

There was the suggestion that some genetics information is of low interest to most recipients unless they are pregnant or planning a family. Such an explanation may account for the lack of success of the project. It is possible, though, that those who required the information, and who may have had the most interest, did in fact gain from the project, but its success in reaching this audience was not measured. This will be discussed in the next section.

Higher profile media outlets such as television were suggested as possible ways of improving the project, along with the targeting of information to those who would be most receptive (e.g. females of reproductive age).

It was noted that health professionals were commonly referred to as sources of information about hereditary disease. The authors felt this emphasised the importance of GPs as sources of information about genetic diseases.

Contained in Table 6, on page 50, is a summary of the main strategies used by Walpole *et al* to raise awareness among the general public and health care professionals. It includes their advantages, disadvantages and some suggestions for improvement.

## Analysis

Walpole *et al* conclude that the project showed "routine educational and health promotion strategies will not be enough to achieve desired levels of knowledge and attitude change." This statement is true in that the general public did not appear to be reached by the strategies used. This will be discussed later.

The health care professionals, however, were responsive to the efforts of the HDP. And if this group gains, so too will the affected individuals and families, through their interaction with the health carers. The health care professionals are a group which has been identified as important communicators of genetics information but generally deficient in knowledge (Scribanu *et al*, 1991; Hofman *et al*, 1992; Garver *et al*, 1993; Hofman *et al*, 1993; Boulton and Williamson, 1995; Euroscreen, 1997; Holtzman and Watson, 1997; Kopinsky, 1997; Stephenson, 1997). The use of the strategies incorporated into the HDP for informing health care professionals should not be dismissed.

Health professionals, particularly GPs and CHNs, referred their patients to the genetics outreach clinic, and most responded in a survey that they felt genetic issues were important. Whether they felt this way at the beginning of the project was not mentioned. A pre-project survey to find out the GPs and CHNs attitudes towards the importance of genetics in their practice should have been carried out. It is possible there was already substantial interest, but in light of the findings that health care professionals know little about such issues (Scribanu *et al*, 1991; Hofman *et al*, 1992; Garver *et al*, 1993; Hofman *et al*, 1993; Boulton and Williamson, 1995; Euroscreen, 1997; Holtzman and Watson, 1997; Kopinsky, 1997; Stephenson, 1997), it seems unlikely. One would also assume the coordinators of the project perceived there was a need for the effort, otherwise it would not have been undertaken.

There was no effort made to assess whether understanding and knowledge about genetics increased. It may be argued that this is a very important aspect of education, since the health care professionals need to know when genetics services are required, and an understanding of why they are referring their patients.

Ninety two percent of GPs who responded to the surveys thought there was a need for further education in their profession, and could see a role for themselves in managing patients with hereditary disease. This suggests that distributing pamphlets, running seminars and meetings, and informing health professionals about the existence of services and information, as was the approach taken by the authors, was effective and should be continued.

It seems logical that this approach would be effective for health care professionals. This group is more likely to incorporate genetics into their work when the information comes tailored to their needs, with obvious relevance to

their practice, and from a reliable source. Letterbox drops, public posters, media coverage, and advertisements are unlikely to have much effect, as they are not obviously applicable, nor are they designed to demonstrate the importance of genetics in clinical practice. The only disadvantage of pamphlets is that they are static and may not attract as much interest as a more dynamic approach such as a video or CD-ROM. Obviously cost is a limiting factor for these last initiatives.

Seminars and in-services were held for the health care professionals, and good attendance was reported at these. This approach is effective because the information is delivered in a visual and interactive form, with participants able to question the experts. There was no need for information to be prepared by the HDP, merely the date, time and place advertised. However, attending would have required the health professionals take some time from work, which may have been a problem. A further drawback is that only those in the audience received the information, limiting the number which were reached. If shorter, more frequent talks were organised, a larger number of busy professionals may have been able to attend. Videotaping the talks would have allowed those who missed the talks to watch them at their leisure. To increase the amount of seminars given, members of each profession could be trained to give the seminars themselves, rather than the expert.

It might be argued that the intentions and thoughts of this group are not as important as their actions - would they continue to inform and refer their patients once the regular reminders disappeared? Are good intentions enough? The answer to such a question can only be determined by follow-up studies.

If indeed the general public gained little from the project (which the small amount of post-test surveys indicated they did), then it would suggest that the strategies undertaken in this project were a waste of time.

Considering the methods used by the HDP could provide some insight into why there was so little success in educating the general public. The distribution of pamphlets to mailboxes would have reached all of the households in the target area, and the recipients were able to read it at their leisure. But in how many cases would the pamphlet have been dismissed as another piece of junk mail, even if it looked professional and was concerned with a serious topic? Households receive so many requests for financial support through the mail that many people would have thrown it away without even reading it, especially with a reply-paid envelope, which usually accompanies letters seeking financial outlay. In a

household with more than one adult, the chances are that the first person to read it (if they did read it at all) would have thrown it away if it did not interest them (i.e. they were not considering having children, or did not know anyone with a genetic condition). Which leads to the conclusion that even though the information theoretically reached all residents in the area, it may have only been read and absorbed by a small percentage of the population. The finding that less than 21% of the population remembered receiving anything in the mail supports this conclusion.

The posters and pamphlets that were distributed around public places also theoretically reached a large number of people, but again there is no guarantee any notice was taken of them. Busy people may have glanced at them and then ignored or forgotten what they saw if they had no interest in the information. Since they were static, the posters needed to contain something to attract and hold interest, such as appealing images, or attention-grabbing headlines.

The genetics outreach clinics were accessible for those with time to visit them, and allowed for one-on-one information delivery. They were a good idea for those in need of information, but did not reach a large audience. Having to actually attend the clinic may have deterred potential users, although the telephone line would assist some people.

The utilisation of the media was a strategy which could be expected to have some success, as there is considerable interest in medical stories (CSIRO, 1997; Durant, *et al*, 1989). Newspapers, radio and television reach a large audience, one which is generally interested in the information. Stories showing the human side of genetic research, such as its application to treating hereditary disease, would have generated interest and reached a number of people. As for the GEP, high profile speakers could have appeared on television and radio programs, and a news story about a development in genetic research could have been produced.

A drawback to this project is the way the coordinators chose to measure its effectiveness. Surveying health care professionals gave positive results, but this group were known to have received the information, and were likely to have an interest. The general public were interviewed randomly in a shopping centre, and only 250 out of 51,000 people (0.5% of the total population) were reached at the conclusion of the project. Whether this number is sufficient to assess the success of the project is debatable.

The point must also be raised as to whether a smaller subset of people, the affected public, actually did gain from the project. Perhaps a survey of the changes in awareness within this group might have yielded more encouraging results, since these people might have taken much more notice of the distributed information. If the use of the genetics outreach clinics is any indication in this project, it reached at least some people. It must be asked whether this group should in fact be the main priority of genetics education projects such as this one, since they will be the most affected if they do not find out until it is too late for the information to be acted upon.

There was no attempt made to assess the effectiveness of the material itself in communicating about hereditary diseases. Perhaps additional post-project surveys could have been carried out on a group of people who were known to have read the information. This might have shed some light on whether people learnt from the material, and where improvements could be made. No mention was made of whether community consultation was sought during the design of the materials, so it is possible that what the coordinators thought was appropriate was in fact far from it. Studies have shown that this has been the case in other parts of the world (Turney, 1995).

Seminars could have been arranged at child health centres, for both the public and health professionals. The static displays could have been staffed and passers-by encouraged to begin constructing their family health tree on the spot. If mailbox drops were to be continued, perhaps they could be directed at areas where more receptive audiences resided, such as new housing estates where couples of child-bearing age were likely to be settling.

Some of the ideas suggested for the GEP, AGSA and the GAW could be incorporated into the HDP (see Chapter 3 for these). If finances permitted, the services of marketing experts could have been utilised, since reaching a wide audience and attracting their interest is essentially this field. Appealing images such as very cute babies in unique poses (such as in flower pots or dressed up as bees) have been utilised to sell a number of products, so why could they not be adapted to possibly benefit those starring in them? Promoting awareness as part of a wider campaign such as Jeans for Genes Day would be another strategy that could increase the visibility of the efforts.

| | The Hereditary Disease Project and its components |
|---|---|
| **Audience** | The general public, health care professionals, the media |
| **Aims** | Raise awareness and educate<br>Assess the effectiveness of different approaches to educating health care professionals and the general public |
| **Advantages** | A number of different strategies tested |
| **Disadvantages** | Evaluations and surveys were not adequate<br>Individual strategies could have been better |
| **Improvements** | Different evaluation methods<br>Target specifically the affected public<br>Use higher profile media outlets |
| | **Kits for health care professionals** |
| **Audience** | Health care professionals |
| **Aims** | Inform<br>Encourage incorporation of genetics into their practice<br>Promote genetics services |
| **Advantages** | Relevance to their practice made obvious<br>Information tailored to their needs<br>Information in a documented form for easy referral<br>Able to be photocopied |
| **Disadvantages** | Static, may lose the interest of the readers |
| **Improvements** | Kits incorporating other mediums e.g. CD-ROMs, videos |

**Table 6: A summary of the main strategies used by Walpole and colleagues in the Hereditary Disease Project**

| | The Hereditary Disease Project continued |
|---|---|
| | **Seminars and in-services for health care professionals** |
| **Audience** | Health care professionals |
| **Aims** | Ongoing genetics education<br>Encourage use of genetics services<br>Updates on relevant technology |
| **Advantages** | Visual and interactive delivery of information<br>No need to distribute information, only notify about date and time of talks |
| **Disadvantages** | Require time out of work to attend<br>Amount of people reached is limited by size of audience |
| **Improvements** | Shorter, more frequent talks<br>Video taping for loan to those who missed the seminars<br>Train certain members of each profession to deliver the seminars themselves |
| | **Pamphlet distribution to mailboxes** |
| **Audience** | General public |
| **Aims** | Inform about project<br>Raise interest in genetics, services and testing |
| **Advantages** | Theoretically every member of community comes into contact with information<br>People are able to read the information at their leisure |
| **Disadvantages** | Pamphlets may not be distinguished from junk mail, and thrown away<br>Cannot be sure information is received<br>Costs of printing and distributing pamphlets which could be simply thrown away |
| **Improvements** | Target areas known to be high in residents of child-bearing age e.g. new housing estates |

**Table 6 continued: A summary of the main strategies used by Walpole and colleagues in the Hereditary Disease Project**

| | Hereditary Disease Project continued |
|---|---|
| | **Pamphlets and posters in strategic public places** |
| **Audience** | The general public |
| **Aims** | As for mailbox drops |
| **Advantages** | Potentially are seen by those to whom they are most relevant<br>Visual stimulation |
| **Disadvantages** | May not be seen or remembered, especially by busy families<br>People may not have time to stop and look at posters<br>Static information - so must contain something to gain attention and hold interest |
| **Improvements** | Make posters very appealing and eye-catching e.g use photographs of cute babies |
| | **Genetics outreach clinics** |
| **Audience** | Affected public, or those potentially affected |
| **Aims** | Provide specific genetics information for interested people |
| **Advantages** | Accessible<br>One-on-one information delivery, ensuring sensitivity and accuracy, and the possibility of asking questions |
| **Disadvantages** | Have to physically attend the clinic<br>Must book session - may not be suitable times available<br>Might be business hours only, which does not suit many people<br>Only reach a small number of people |
| **Improvements** | Ensure they are open at convenient times |

**Table 6 continued: A summary of the main strategies used by Walpole and colleagues in the Hereditary Disease Project**

| | Hereditary Disease Project continued |
|---|---|
| | **Advertisements and stories in newspapers, on radio** |
| **Audience** | The general public, the affected public |
| **Aims** | Raise awareness about genetic conditions and services such as genetic counselling |
| **Advantages** | Potentially a very wide audience<br>Human interest stories can be produced<br>Newspaper articles can educate without people realising it and becoming bored |
| **Disadvantages** | Not everyone reads the newspaper or listens to the radio<br>Advertisements in newspapers and on radio are often ignored<br>Possibility of inaccurate reporting<br>Stories and advertisements only appeared for three weeks |
| **Improvements** | Geneticists could write stories for newspapers<br>Use high profile speakers on informative or chatty radio programs<br>Ongoing production of stories |

**Table 6 continued: A summary of the main strategies used by Walpole and colleagues in the Hereditary Disease Project**

# Chapter 5: Overseas initiatives

# The Gene Shop

## About the Gene Shop

The Gene Shop was opened in February 1997 in the Departure Lounge of Terminal 2 at Manchester Airport in England. It was designed to take education about genetics and inheritance to the general public in a form and location that was easily accessible. The shop was a joint project between the Centre for Professional Ethics at the University of Central Lancashire and the Royal Manchester Children's Hospital (RMCH) (Stephenson, 1998) and was funded by the European Commission's Biomed Program (Levitt, 1998). There was a full-time coordinator and a number of rotating staff from the Department of Clinical Genetics at the RMCH (Levitt, 1998).

The aims of the Gene Shop were multiple (Levitt, 1998). It was hoped the shop would provide easily accessible public education that would satisfy and encourage curiosity about genetics and the surrounding issues, as well as reduce mystique and media hype about genetic diseases. In addition, it was to function as a pilot project to test the effectiveness of such an approach, and its success was to be evaluated after a year of operation.

It was not the intention of the shop to provide genetic counselling, but rather to raise awareness of the existence of such services and provide information about where they could be sourced. The staff of the shop all had experience in dealing with families referred for counselling or diagnosis so inquiries could be dealt with knowledgeably and sensitively.

Several locations were considered for the shop, including a shopping centre, an airport, a mobile unit and a few sites around which the shop would move (Levitt, 1998). Each site had its advantages and disadvantages, and in the end Manchester Airport was chosen. The main reasons for this location was the large and constantly changing population of the airport, which came from a wide geographical area, and good public transport and motorway access. It was accessible to the non-travelling public, and the visitors to the airport had enforced leisure time while they waited for their flights. It also provided a European dimension, which was seen as desirable. The main disadvantages in the airport

site were that many visitors would not be local, meaning they might not return for a long time, if at all. Measuring the effect of the shop on the community as a whole would be difficult too, because the population was transient (Levitt, 1998).

The shop itself consisted of two rooms, a larger one containing displays and information, and a smaller, private room where videos were shown, telephone enquiries taken and more private discussions carried out. The shop was open between 8:30am and 2:30pm on Monday, Wednesday, Thursday, Friday and Saturday, and was always staffed by two people. On the glass-front of the shop was a transfer about Queen Victoria's family tree. Inside were four interactive touchscreen computers, which ran programs from the Science Museum and the Wellcome Trust. The programs were called *Genetic Choice, A Sickle Cell Story, Variable Variables* and *Jeannie Jones: my interactive guide to Gene Therapy* (Levitt, 1998).

Permanent poster displays were present, and topics included basic genetics (*What is a gene?*), genetic counselling, haemophilia in the British Royal Family, muscular dystrophy, and red-green colour blindness. At the rear of the shop were temporary exhibits that changed monthly. These included displays on haemophilia, CF, familial cancer, genetic aspects of deafness and blindness, and multifactorial disorders. Public lectures complementing the temporary displays were also given (Levitt, 1998).

Leaflets about particular genetic conditions and genetics in general were found near the relevant displays, and support groups provided displays with information and stories about people affected by genetic diseases (Levitt, 1998). A noticeboard presented clippings of recent news stories about genetic issues (Stephenson, 1998).

Before the shop opened, there were fears that groups or individuals opposed to genetic testing or medical abortions might target the shop. To provide a broad view, there was an opinion corner which was offered to any group wanting to display materials expressing their point of view, such as the Right to Life groups (Levitt, 1998).

During the first nine months of operation, nearly 9000 people had visited the Gene Shop. It was found through interviews and questionnaires that while some of the visitors had an interest in a particular genetic disease or counselling, the majority were simply curious or were passing time while waiting for a flight (Stephenson,

1998). As reported by Stephenson (1998), Dr Mairi Levitt, who carried out the Gene Shop evaluation, believes this means "we're getting people who wouldn't otherwise be currently seeking advice."

The Gene Shop was initially only funded for a year, but recently an application was placed for further financial support to continue the airport shop and create a mobile Gene Shop to take to schools, training colleges, university campuses and country fairs (Stephenson, 1998). Whether this eventuated was not known at the time of writing.

## Analysis

The Gene Shop was a non-mobile education program that reached those who were travelling through Manchester airport. In Table 7, on page 58, a summary is given of the aims, advantages, disadvantages and improvements that could be made to the shop. It was stated that the shop would be accessed by the local population, but it is possible that those who were not using the airport for travelling would be reluctant to visit this site.

The airport location meant large numbers of people with enforced leisure time while waiting for flights would be able to visit the shop. A single location gave the opportunity to present the information in an interesting, engaging way, by the use of interactive and visually stimulating exhibits. Having staff available to speak to provided the opportunity for visitors to ask questions, and staff could immediately identify any problems with the display material.

As assessed by surveys, the majority of the users were those without a pre-existing interest in genetics, making the Gene Shop the only project described in this study whose audience was almost primarily the general public. Having reached nearly 9000 people in nine months is a significant achievement and it demonstrates that the public do have an interest in the topic when the information is convenient and presented in a form which is easy to access and understand.

It was quite different from the other programs described in this study (besides Genetics Awareness Week) because it was at a fixed site, with users having to travel to the shop rather than the information coming to them. This constitutes the main drawback of this approach. Only those visiting Manchester airport or able to access it easily would have benefited from the project, as information was not distributed from the shop to households. How well it was advertised in the local

area is not clear, but if it was not well-known, some of its potential audience would be lost.

If the shop could be extended effectively to the local community, education and awareness could be further improved. Displays that were no longer being used could be distributed to schools, community health centres and shopping centres. A mobile Gene Shop, as had been proposed, would further extend the capabilities of the facility. Some of the exhibits could probably be temporarily relocated to fairs and shows, enlarging the potential audience.

Information sheets and resources could be distributed on request to members of the community, in a similar manner to the NSW GEP. A video library could be established, for loan to local residents. Copies of the interactive computer programs could be made and loaned to schools for teaching purposes. A library of genetics resources set up in the shop could be a useful resource for both students and the media. An internet site could be set up, with similar content to the posters and pamphlets on display in the shop. Staff could travel short distances to speak to professionals, students and the public about genetics issues.

All these suggestions involve extending the shop's activities from its one location to the general community, and providing more widely spread genetics education. It is possible the shop is limited in what it can do, and keeping it as a single site is more appropriate and feasible. The outcomes of Dr Levitt's evaluation of the shop, undergoing printing at the time of writing, will direct the next steps for the project, and it will be interesting to see what her recommendations are.

| | The advantages and disadvantages of the Gene Shop |
|---|---|
| **Audience** | The general public, the affected public, policy makers |
| **Aims** | Provide genetics education in a single, accessible location<br>Assess success of the approach |
| **Advantages** | Wide audience, with enforced leisure time<br>Information potentially presented in an interesting, engaging way<br>Accessible<br>Multiple media can be used (e.g. videos, computers)<br>Feedback received immediately |
| **Disadvantages** | Single location<br>No education is taken to the community<br>Must advertise for local residents to be aware of it<br>Many visitors never return so no chance for them to follow up initial interest |
| **Improvements** | Send information out to the community<br>Re-use displays at schools and in health care centres<br>Advertise well<br>Create a mobile shop to travel around |

**Table 7: The Gene shop and its main advantages and disadvantages**

# Genetics Week in Delaware

## About Genetics Week

Genetics Week in Delaware was an initiative undertaken by a local geneticist when he realised that many of the local health professionals, including an obstetrician, had limited knowledge of inherited diseases. To overcome this, a week of seminars and conferences dealing with relevant genetics developments was organised, to which all the local health professionals were invited. The project was reported in the *American Journal of Human Genetics* in 1992 by Borgaonkar, the organiser of the event.

The first Week was held in the mid-1980's and included the topics of genetics and its relation to social work and nursing, neurology, special education, religious beliefs, ethics, psychosocial issues, paediatrics, and cancer. Subsequent weeks were held in 1988, 1990 and 1992, with Borgaonkar aiming to run them biannually. The focus was on developments in genetics and how they applied to health care.

Genetics Week drew 80% of the health-care professionals invited to the program. Several speakers published material from their talks in the *Delaware Medical Journal*, and Borgaonkar reported that the week received favourable comments in the local media and from the professional community. A similar program was inspired in Yugoslavia, and according to Borgaonkar, some of the visiting professionals from the USA expressed the thought that similar programs in other parts of the country would heighten knowledge and awareness of genetic developments.

Searches of the internet and medical databases failed to uncover any further Genetics Weeks in Delaware, so whether the initiative continued past 1992 is not known.

## Analysis

Genetics Week in Delaware was a program with a very specific focus and target audience. It informed about developments in genetics and their application to health care. Attending the week were health care professionals from a variety of

medical fields, not necessarily those traditionally associated with genetics. Table 8, on page 61, is a short summary of the main aspects of the project.

The success of the program lies in its focus on this group of people and application to their fields. The talks could be tailored to the audience, with emphasis on genetics and health care. By running the talks during a time allocated to professional education, a larger audience could be attracted, with less disruption to their work.

Developing kits with updates and sources of further information would have allowed the messages from the seminars to be distributed to any who were unable to attend. Additionally, videotapes of the talks could have been made, to serve a similar function to the kits. There could have been seminars aimed at educating representatives from institutes or professions who could pass on knowledge gained during the Week. Such seminars would not need to necessarily be during the designated week, and could be ongoing.

| | Genetics Week in Delaware: an overview |
|---|---|
| **Audience** | Health care professionals |
| **Aims** | Demonstrate how genetics is applicable to many aspects of health care, show how to incorporate it<br>Promote understanding and use of genetics services<br>Provide updates about genetics developments |
| **Advantages** | Focussed on particular group, making organisation simpler<br>Content is directed at being relevant for the one group only<br>Seminars incorporated into regular professional educational times<br>Practical information on how to incorporate genetics into medical practices |
| **Disadvantages** | Only reaches a small, specific audience |
| **Improvements** | Include some talks for the general public |

**Table 8: An overview of Genetics Week in Delaware**

# Chapter 6: Summary and Conclusions

The question raised at the beginning of this sub-thesis was:

*Is information about genetic diseases and testing readily available and suited to the needs of the target audience(s)?*

The first part of the question was answered in Chapter 1 - yes, there is information and it is readily available to anyone who telephones the NSW GEP. There is not a great deal of readily accessible information available from any other source except the internet which, as stated in Chapter 1, is not accessible to all groups of people.

What form the information produced by the GEP takes, how it is advertised and distributed, and whether it is suited to the needs of the target audiences was the main subject of this study. For comparison and ideas for novel approaches to educating, five other awareness or education projects were studied.

In Chapter 1, two audiences for education and awareness projects were identified - the general public and the interested public. The findings with regard to each audience will be considered separately, and conclusions will be drawn after each has been discussed.

## The interested public

This group was defined in Chapter 1 as comprising those individuals and families who are directly or indirectly affected by a hereditary condition. Also included in the interested public are health care professionals who work with affected families.

All of the programs described in this study provided information to the interested public. Aiming to inform affected individuals and families directly, without the involvement of a health care professional, were the GEP, GAW, AGSA and the Gene Shop. The GEP produced fact sheets and the *Genetics Resource Book*, maintained an internet site, and participated in GAW. At the GAW, seminars

about genetic conditions were given. AGSA advertised and distributed information directly to some of its clients, while the Gene Shop was a single site project, to which affected families could go in search of information.

The information provided by the GEP to the affected public was accurate, sensitive and designed with this group in mind. The only problem with the information was that its existence was not advertised extensively to those who might need it. When directly targeting the affected public, programs must advertise their services, to ensure people know that information is available. This may be directed specifically at people likely to come into contact with a genetic condition, or as part of a wider education project, such as one aimed at the general public. It is not of great concern that the GEP does not carry out much advertising directly to the affected public because as discussed below, there is a better way of reaching the affected public - via the health care professionals.

A substantial amount of the GEP, the HDP, and Genetics Week in Delaware's efforts were aimed at the affected public via the health care professionals. In-services for GPs and other health care workers are run by the GEP, and health care professionals are supplied with fact sheets and the *Genetics Resource Book.* The HDP incorporated similar strategies, running in-services and seminars, distributing information kits, brochures and written updates. Genetics Week in Delaware was a much smaller scale effort, which reached health care workers during their professional education periods by way of seminars.

The health care professionals are an important group. Most people affected by a genetic condition will interact firstly with their GP, who must be knowledgeable about the diagnosis and treatment of genetic conditions, as well as up-to-date about where further information can be found. The patient may then be referred to a specialist in the medical field, who also must have knowledge of the condition and where the patient might go for further information. If the health care professionals are not knowledgeable about services like the GEP, this major link to the information will be lost. It is therefore critical that programs be directed at raising awareness within the medical community. Not only should doctors be aware of services such as diagnostics and education programs, they also need to be regularly updated about the conditions themselves. Until the GPs are fully

informed, genetic conditions will go undiagnosed and patients will be left confused.

Strategies directed specifically at the health care professionals are more likely to be successful than those that include this group in a broader education project. In-services and seminars, particularly during regular professional educational periods, are an efficient way of spreading information, as are information kits. This audience is easier to reach than the general public because the individuals work in fixed locations where material can be sent. They are an excellent group to aim educational efforts at because they have a great deal of contact with affected individuals and families and are in a good position to disseminate information.

The GEP directs a substantial proportion of their resources towards the health care professionals and it is my conclusion that these efforts are potentially their most valuable and effective. The information currently distributed is suited to the needs of both the health care professionals and their patients, and the in-services carried out are highly useful to ensure the health professionals are kept informed. Whether these efforts reach a sufficient number of health care professionals, particularly GPs, may be questioned, however. My family GP obviously had not been reached by the program.

The GEP's projects to reach health care professionals should be continued and widened. Genetics Week in Delaware and the HDP both had positive outcomes from their projects, and the aspects of their strategies which are not already in use by the GEP should be incorporated into that program's approaches. Table 9, at the end of this section, suggests several strategies the GEP could undertake to improve their service.

## The general public

These are people not affected by a genetic condition, essentially comprising the rest of the population. Included are teachers, school and university students, and the media, with the latter being an important link to the general public.

The NSW GEP, GAW, the HDP and the Gene Shop all directed differing proportions of their resources at the general public. The approaches taken were vastly different. The GEP developed an internet site, displayed at shows, utilised the media and participated in GAW. GAW was a series of seminars over a weekend at a central venue, accompanied by displays and a small amount of written information. In Western Australia, the HDP took its message to the community in the form of pamphlets and posters, and newspaper and radio advertising. Taking a completely different approach was the Gene Shop in England, which was an ongoing, single-site genetics information source situated in an airport and open to the general public.

As discussed in Chapter 2, it is important there is public awareness of genetic conditions. If the community is to be supportive of those affected, able to participate intelligently in debates about the future of testing, and understand the implications of mail-order genetic testing, there will have to be some effort made to draw attention to the issues. Two of the GEP's aims are to provide current and relevant genetics information, and to promote the access and use of genetics services in Australia (NSW Genetics Education Program, 1998b). Since it is not specified that the intended audience is only those affected by genetic conditions, it would seem apparent that the GEP feel the general public to be an important audience.

The general public, however, received little information that was tailored specifically for them. For information to effectively reach them, it must be easily understood and interesting or relevant to their lives. It must be accessible, because those without an interest are unlikely to seek it out of their own accord. The GEP's stand at the Sydney Royal Easter Show took the information to the public, but only to those who attended the event. In addition, the main drawcard of the stand was a survey testing people's knowledge rather than teaching them anything about genetics. The seminars held in GAW reached an even smaller number of people and were unlikely to have attracted anyone without a pre-existing interest in the subject. They also required attendance at the event, which could have been a deterrent to many. Neither of these efforts took information about genetics to a large number of people in an appealing manner.

These observations indicate that the GEP is not providing information that is suited to the needs of the general public. Therefore the answer to the second part of the research question posed in this study is that not all information available is suited to the needs of the target audiences. That which is directed at the interested public is suited, but not that which is aimed at the general public.

It seems likely that the general public are of lower priority to the GEP than the interested public, and this is understandable, since those affected by genetic conditions are in most need of information and support. However, if effort is going to be made to reach the general public, it might as well be as effective as possible.

Promoting awareness through the media is likely to reach a wider and more receptive audience, mostly due to the channel through which it is presented. This avenue should be more actively pursued if the GEP hopes to bring about wider community awareness of hereditary conditions.

The HDP's poorly-received attempts at raising awareness among the general public through mailouts and posters illustrates the need for more interesting, relevant and dynamic approaches. Information needs to be distributed via a variety of channels, and reach all the different cultural and socioeconomic groups. The Gene Shop was able to make its information interesting and interactive, but unfortunately only those travelling through Manchester airport could take advantage of it. It is likely that the lower socio-economic groups may have missed out, because they were less likely to travel by aeroplane. The single site was a good start in taking genetics to the public in a user-friendly form but to reach all community groups it needs to be in a location which is accessible to all.

The ideal education and awareness project for the general public would include the most successful aspects from each program or project described in this study. A multi-faceted approach is likely to be most successful, one which directs its communication via all channels, such as routine information dissemination (poster and pamphlet distribution), the popular media (television, newspapers and radio), the internet, a fixed location source of information (a shop or a stand at fairs) and

advertising campaigns. Some of the methods the GEP could undertake to improve awareness among the general public are outlined in Table 9.

While the GEP is in a good position to carry out efforts to raise awareness, it should not be their responsibility entirely, especially as they have the affected public to serve as well. Perhaps individual genetics services across the country could devote a little of their time to general community education. Collectively, the efforts of a large number of professionals could constitute an effective awareness and education campaign. The Human Genetics Society of Australasia is a collection of clinical geneticists and researchers who are involved in a number of activities, and one of these is the promotion of public awareness of human genetics (Human Genetics Society of Australasia, 1998a). An organisation like this could help encourage and coordinate a nation-wide effort, and are in fact in a better position to do so than the GEP, due to the fact that there are more members and they are scattered across the country rather than based in one location.

In summary, an answer to the research question has been gained in the course of this study. There is information about genetic diseases and testing available, primarily from the NSW GEP, and it is suited to the needs of the interested public. Effort could be made to further increase the number of health care professionals, particularly GPs, who are knowledgeable about genetic conditions, and this would help ensure that all those affected by hereditary conditions are correctly diagnosed and informed about their illness.

The information provided by the GEP for the general public was not sufficiently suited to their needs, lacking wide distribution, interest and relevance. Other programs studied demonstrated there were more effective strategies which could be undertaken, and it is recommended that the GEP incorporate some of these into their efforts.

**Table 9: Suggested strategies to improve communication of information by the GEP to a) the affected public**

| Strategy | Who it would reach | Benefits of this approach |
|---|---|---|
| Posters and brochures in GP surgeries* and other community clinics | Affected individuals and families | People informed where they are diagnosed |
| Production of videos and the maintenance of a video library for distribution by the program | Affected individuals and families, health care professionals | Interesting, visual method of presenting information and informing a number of people without direct contact |
| In-services for health care professionals, particularly GPs* | Health care professionals and, indirectly, the affected families | Improve knowledge and awareness within the medical profession |
| Teaching kits for genetics units to educate health care professionals in the local area* | Health care professionals and, indirectly, the affected families | Improve knowledge and awareness within the medical profession. Allow for more education without the direct involvement of the GEP |
| Information pamphlets mailed directly to GPs* | GPs and, indirectly, the affected families | GPs made aware of genetic services and the GEP |
| Advertisement of the service and *Genetics Resource Book* in local medical journals | Health care professionals, and indirectly, the affected families | Better knowledge within the medical community of the service and the book |
| Advertisement of the *Genetics Resource Book* to health clinics | Health clinic staff and through them, the affected families | A valuable resource more widely utilised |
| Kits for health care professionals about incorporating medical genetics into their practice | Health care professionals, and indirectly, the affected families | Specific information as to how to incorporate genetics into clinical practice can be conveyed |

**Table 9 continued: Suggested strategies to improve communication of information by the GEP to a) the affected public**

| Strategy | Who it would reach | Benefits of this approach |
|---|---|---|
| In-services aimed at teaching health care professionals how to educate colleagues | Health care professionals, and indirectly, the affected families | More education for less effort by the GEP |
| Involvement in medical training at university | Future GPs and affected families a few years later | Reach GPs early, and a large number at once in a lecture theatre or tutorial |
| Seminars for GPs with prominent speakers about developments in research and treatment | GPs and affected families | Keep GPs up-to-date, increase knowledge and interest in the field. Ongoing professional education |

* strategies which are currently or previously undertaken by the GEP and which could be scaled up or built upon

**Table 9 continued: Suggested strategies to improve communication of information by the GEP to b) the general public**

| Strategy | Who it would reach | Benefits of this approach |
|---|---|---|
| Posters and brochures about prenatal and carrier testing in family planning and child health clinics | Young couples and families planning to have children | Target a specific audience and raise their awareness about the potential benefits of testing |
| Advertisements in family magazines about prenatal and carrier testing | Young couples and families planning to have children | Target a specific audience |
| Media stories, media assistance* | The general community | Information delivered directly to public in a form which can be easily understood and is interesting |
| Fixed site or mobile information stand (like the Gene Shop but on a smaller scale) (A similar but smaller scale initiative was the stand at the Sydney Royal Easter Show) | The general community | Information is delivered to the people, and can be made interactive and visually pleasing. Visitors can talk to a trained professional immediately and have questions answered. A variety of information can be on hand to supply if requested – allows the distribution of material which is suited to the needs of the visitor |
| Teacher education/in-services* | Teachers and students | Begin learning at a young age, before misconceptions can arise. Teachers and students kept up-to-date |
| Seminars to instruct teachers how to train other teachers | Teachers and students | Spread education further than if simply educate a few teachers |
| Teaching kits | Teachers and students | Keep teachers up-to-date. Make it easy for them to incorporate genetics into their lessons. Encourage interest from students |
| Displays in science centres | The general community | Learning in an informal, recreation environment. Interactivity is possible |

# Limitations and further work

This study made an important first step towards identifying effective methods to inform the public about genetic conditions. Further studies could address several research areas that have not been discussed in detail in this work.

No attempt has been made to analyse or measure the effectiveness of the material itself in informing. There were no interviews with the recipients of the information, so the adequacy of the information could only be surmised from looking at what was available and any documented evidence of public response. Whether the information is effective is an important issue, since large-scale education campaigns will be useless if the distributed information is confusing or misleading. There is much more to communicating than simply throwing material at people. Further work in this area could include interviews or analyses of the material itself, and is likely to lead to further suggestions for improving community education and awareness projects.

The event that motivated this study was my mother's and my family GP's lack of knowledge about a hereditary condition and where information might be found. The research work carried out focussed on what information was provided, and did not address the question of whether our GP's response was typical of other GPs or health care professionals. The literature cited in Chapter 2 suggested that it was typical, but a survey could have been carried out to address this question. What the health care professionals' level of knowledge about genetic conditions and information sources were, how they found out about them, and which patients they referred, could all be considered. This would provide an insight into just how much effort needs to be put into professional education, and which strategies will be most effective in reaching this group.

A survey of the general public could be carried out to assess how much is known about hereditary disease and relevant sources of information. Their interest in learning about genetic conditions could also be measured. How affected families went about finding information is another relevant study, which may help in the design and targeting of information to this group. Whether they felt that the information given was adequate is also worthy of consideration.

The perceived reliability of information found on the internet is something which may be of interest if the use of that medium continues at its current rapid rate. It is

possible for anyone who so desires to place material on the world wide web, regardless of its accuracy or their background. Taking medical information found on the internet as truth could be quite dangerous. It is possible that even if accurate information about genetic conditions is placed on the internet, it will be dismissed as unreliable, despite the information being credited to a legitimate organisation. Research into this area may uncover some interesting facts, which could be well worth considering when looking at using the internet.

# Appendix: Resources available from the NSW Genetics Education Program

Specific resources available to the public (NSW Genetics Education Program, 1998b) were:

- *Genetics Resource Book.* Published annually, it contains general educational information about heredity and genetic conditions as well as contacts for people seeking help;
- *Do you know your genes? A do-it-yourself guide to drawing your family health tree* pamphlet;
- *Genes and Cystic Fibrosis - Basic Facts About Chromosomes, Genes and Cystic Fibrosis* booklet;
- *A simple vitamin called folate taken before pregnancy as well as in early pregnancy can help prevent spina bifida in your baby* pamphlet;
- *What you should know about inherited disorders* pamphlet about genetic counselling, in 16 languages;
- *Predictive testing for Huntington Disease* information kit;
- *Predictive testing - Information for Physicians* pamphlet about Huntington Disease;
- *A blood test to determine the risk of certain problems in your pregnancy - the Maternal Serum Test* pamphlet;
- *Some questions and answers when your test result shows an "increased risk" of your baby having Down Syndrome* pamphlet;
- *Some questions and answers when your test result shows an "increased risk" of your baby having a neural tube defect such as Spina Bifida* pamphlet;
- *Checking your baby's health before birth* pamphlet in 13 languages;
- *Special tests for your baby during pregnancy, Chorionic Villus Sampling (CVS), Ultrasound and Amniocentesis* booklet;
- *Support After Foetal Diagnosis of Abnormality (Safda)* pamphlet;
- *Prenatal diagnosis - towards an informed decision* - an educational video produced for use in the community; and
- Genetic information 'fact sheets' which contain information concerning a particular disorder and support services, written using the most current data available. There are over 500 fact sheets currently distributed by the GEP.

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