GUIDELINES FOR
HUMAN GENETICS SOCIETY OF AUSTRALASIA (HGSA)
TRAINING AND CERTIFICATION IN GENETIC COUNSELLING
APRIL 2002

CONTENTS **Page No.**

SECTION 1. OVERVIEW

A.	Introduction – Genetic Counselling	1
B.	Duties of a Genetic Counsellor	2
C.	HGSA Board of Censors for Genetic Counselling	3
D.	Board members / contact details	4
E.	Training and Certification	6
F.	Training for Counsellors in Cancer Genetics	7

SECTION 2. REQUIREMENTS FOR PART 1

A.	Genetics	8
B.	Counselling	10
C.	Guidelines for reading courses	12
D.	Application fee for Part 1	12
E.	Application forms for Part 1	14

SECTION 3. REQUIREMENTS FOR PART 2

A.	Logbook for general Certification	26
B.	Logbook for cancer Certification	28
C.	Logbook examples	30
D.	Long cases	34
E.	Referencing long cases	35
F.	Pedigrees	37
G.	Long case framework	40
H.	Supervision	45
I.	Continuing Education	52
J	Application Form for Part 2	53
K	Proforma for Supervisors Reports	55
L	Application Fee for Part 2	61

SECTION 4 MAINTENANCE OF PROFESSIONAL STANDARDS PROGRAM

A. Program Structure 62

B. Credit Categories 64

C. Application Forms for MOPS 67

SECTION 5 RECOMMENDED READING

A. Recommended Reading List 70

SECTION 1: AN OVERVIEW

A. INTRODUCTION - GENETIC COUNSELLING

Genetic counselling is a communication process which deals with the human problems associated with the occurrence, or the risk of occurrence, of a genetic disorder in a family. The process involves an attempt by one or more appropriately trained persons to help the individual or family (1) comprehend the medical facts including the diagnosis, the probable course of the disorder, and the available management; (2) appreciate the way heredity contributes to the disorder, and the risk of recurrence in specified relatives; (3) understand the options for dealing with the risk of recurrence; (4) choose the course of action which seems appropriate to them in view of their risk and their family goals and act in accordance with that decision; and (5) make the best possible adjustment to the disorder in an affected family member and/or to the risk of recurrence of that disorder.

Genetic counselling provides an individual or family with current information and support regarding problems in growth, development and health that may have a genetic basis.

A detailed family history is documented to provide information about the health of family members. Where there is a genetic disorder in a family, the genetic counsellor can estimate the risks that other family members will be affected, or are likely to pass on, the disorder. Often, a person is reassured following genetic counselling when a disorder that was thought to be due to genetic factors is shown to be unlikely to recur in the family.

Genetic counselling may enable the diagnosis of a genetic disorder to be made or confirmed. On the other hand, a family member may be reassured to find that he/she does not have, or is unlikely to develop, the disorder in question. Through the process of genetic counselling the impact and possible effects of the disorder on the individual and their family can be discussed in a supportive atmosphere. Management strategies can be developed and helpful community resources identified.

For an increasing number of genetic disorders it is now possible to determine if an individual is a carrier for a particular mutation in the responsible gene. Where individuals are at risk, the genetic counsellor can provide genetic counselling and arrange appropriate testing. As well, many genetic disorders can be diagnosed before birth. During genetic counselling, prenatal diagnosis and other reproductive options can be discussed to ensure that any decision is made on an informed basis. If a fetal abnormality is identified using prenatal diagnosis, information and supportive counselling is provided.

Where there has been exposure to a potential teratogen (a chemical or environmental agent which can cause birth defects), genetic counselling is an opportunity to obtain current information and support.

There are a number of reasons for which genetic counselling is sought. These include:

- concerns regarding a disorder which runs in a family or a partner's family
- having had a previous child with a disorder
- concerns regarding individuals in the family who have unusual features or multiple malformations
- a woman in her mid-30's or older who is either planning a pregnancy or is already pregnant
- intending parents are close relatives
- an individual or their partner has some concerns about a condition in themselves or their family being passed on to their children
- potential teratogen exposure
- history of stillbirth or recurrent abortion
- detection of carrier status for a mutation (e.g. cystic fibrosis, Duchenne muscular dystrophy, fragile X)
- prenatal diagnosis for a known problem
- unexpected detection of a fetal abnormality during pregnancy

WHO PROVIDES GENETIC COUNSELLING?

Genetic counselling is provided by a team of health professionals, which may consist of clinical geneticists, genetic fellows, genetic counsellors, associate genetic counsellors, fetal medicine specialists, oncology specialists and social workers. They work together to provide information and supportive counselling so that families and individuals may be better able to understand and adjust to the diagnosis of a genetic disorder. Follow up counselling is available to ensure on-going support, review of previous information or answer new questions as they arise.

Clinical geneticists are medical practitioners who have undertaken specialist training in clinical genetics and are certified by the Human Genetics Society of Australasia (HGSA) to provide clinical genetics services.

Genetic counsellors are tertiary trained health professionals with specialist training in genetics and counselling, certified by the HGSA to provide genetic counselling in conjunction with a clinical geneticist.

Associate genetic counsellors are tertiary trained health professionals who are undergoing specialist training in genetic counselling, under the auspices of the HGSA Certification in Genetic Counselling.

Clinical genetics fellows are medical practitioners who are undergoing specialist training in clinical genetics.

Social workers with a special interest in genetics and particular genetic disorders, work closely with clinical geneticists, genetic counsellors and support groups.

Other medical specialists who have undertaken specialist training in another area although have expertise and qualifications in the provision of genetic counselling e.g. fetal medicine specialists, oncologists.

B. DUTIES OF GENETIC COUNSELLORS

The HGSA recommends that any person involved in genetic counselling should be trained in genetics, the principles and practice of counselling, and interview techniques.

The role of a genetic counsellor is varied and will depend on the needs of the particular unit or service of their employment. The genetic counsellor who works in the clinical setting has a primary role in the provision of genetic counselling. Other core duties usually include genetic clinic organisation, intake sessions that may involve visits before a session with the team, follow-up of families and individuals, responsibility for documentation that includes pedigree taking, assessing and recording social, economic and psychological factors.

While the genetic counsellor usually provides genetic counselling in conjunction with a clinical geneticist, there are instances in which the genetic counsellor may provide counselling alone e.g. in the setting of a single genetic disease clinic where the diagnosis has already been established and the counsellor has had specific training in the medical aspects of the disorder e.g. familial cancer. Other areas include screening programs, DNA testing programs, research, genetic education and promotional activities including working with support groups. Some counsellors may have a major involvement in a specific area e.g. genetic education.

C. HGSA BOARD OF CENSORS FOR GENETIC COUNSELLING

In 1990, the Council of the HGSA first appointed the Board of Censors in Genetic Counselling, to serve for a three-year term. This Board's initial composition reflected the development of the training program that was being undertaken. It was comprised of a nominee of the Board of Clinical Genetics, two other HGSA certified clinical geneticists, one person trained in general counselling, and one person who had extensive experience working in a similar role as was being proposed for a genetic counsellor. The Chairperson was the Vice-President of the HGSA (ex officio). The Council appointed a secretary to the Board from amongst the Board's membership.

In 1992 the HGSA Council reviewed the Board's composition. The Board now comprises a maximum of seven voluntary members. There are now five certified genetic counsellors on the Board, one of these having replaced the ex officio position previously held by the Vice President of the HGSA. Other members include at least one Board certified clinical geneticist, and one person trained and highly experienced in counselling, such as a social worker or psychologist. This person should also have experience with clinical genetics services. As Board members rotate off, should more than one candidate be nominated, vacant positions will be filled by a ballot of members of the special interest group, the Australian Society of Genetic Counsellors (ASGC). In order to participate in such an election, ASGC members must be financial members of the HGSA. The Chairperson is appointed from the Board membership.

<u>All correspondence to the Board, including all Part 1 and 2 submissions and general requests for training information should be addressed to:</u>

The Chairperson
Board of Censors for Genetic Counselling
HGSA Secretariat
PO Box 362,
Alexandra, VIC 3714,
Australia.

Assistance pertaining to these Guidelines should be addressed to the local state representative, as noted below:

Board Members:

Annette Hattam (Chairperson)
Annette Hattam (BSc. FHGSA)
Genetic Counsellor
Queensland Clinical Genetics Service
Royal Children's Hospital Health Service District
Herston Rd
Brisbane 4029
Queensland, Australia
tel (61) 7 3636 1686
Fax (61) 7 3636 1987
Email: Annette_Hattam@health.qld.gov.au

Alice Christian
Genetic Counsellor
Central Regional Genetic Services
Wellington Hospital
Private Bag 7902
Wellington South
New Zealand
Tel: (64 4) 479 7547
Fax: (64 4) 385 5822
Email: alice.christian@wnhealth.co.nz

Karen Harrop
Senior Genetic Counsellor
Genetic Services of WA
374 Bagot Road
Subiaco WA 6005
Tel: (08) 9340 1525
Karen.Harrop@health.wa.gov.au

Katie Battesse
Senior Genetic Counsellor
Department of Genetics
The Canberra Hospital
PO Box 11
Woden ACT 2606
Ph. 02 6244 4042
Fax. 02 6244 3021
Katie.Battese@act.gov.au

Julie White
Genetic Counsellor
Queensland Clinical Genetic Service
Royal Children's Hospital, Brisbane
Ph: 61-7-36361686
Fax: 61-7-36361987
E-mail: JulieA_White@health.qld.gov.au

Samantha Wake
Principal Genetic Counsellor
Genetic Health Services Victoria
Royal Childrens Hospital
Flemington Rd Parkville VIC 3052
Tel 61 3 8341 6332
Fax 61 3 8341 6390
Email: samantha.wake@ghsv.org.au

Sharron Townshend[1] (nee Worthington) (state representative WA)
Consultant Clinical Geneticist and
WA Genetic Service
Princess Margaret Hospital for Children
GPO Box D184
Perth WA 6001
Tel: 08 93408828
Fax: 08 93407058
Email: Sharron.Townshend@health.wa.gov.au

WA Genetic Service
King Edward Memorial Hospital for Women
374 Bagot Rd
Subiaco
WA 6008
Tel: 08 9340 1525
Fax: 08 9340 1678

1

D. TRAINING AND CERTIFICATION

In Australasia, the training and certification in genetic counselling is overseen by the Board of Censors in Genetic Counselling (hereon referred to as, the Board), which reports to the Council of the HGSA. All candidates must be members of the HGSA.

Defined knowledge and skill levels in both genetics and counselling can be obtained through successful completion of one of the HGSA accredited Graduate Diplomas in Genetic Counselling or through Board accredited local tertiary course work.

Training to achieve full Board certification is in two parts:

Part 1
Formal academic course work in both genetics knowledge and counselling skills and completion of a clinical placement in a clinical genetics unit.

Part 2
1. Employment with a clinical genetics unit or a clinical unit under direct supervision of a clinical geneticist, where the candidate obtains exposure and experience with clinical genetics, genetic counselling, risk assessment, aspects of genetics laboratories and various clinical genetics research areas.

2. Mandatory genetic and counselling supervision during this period.

3. Documentation of a logbook, long cases, and continuing education are required to demonstrate the candidate's obtainment of essential skills and knowledge.

The opportunity for training and certification in genetic counselling is available to applicants with previous tertiary degrees in other fields. The Board may be asked to consider credit for an individual candidate's previous coursework or training towards Part 1 or Part 2. A candidate may be given partial or full credit for the genetics and/or counselling components of Part 1, depending on the successful attainment of knowledge and/or skills in the Part 1 checklist. The checklist for Part 1 appears on page 17 of this document. The Board will consider applications for HGSA certification by graduates of overseas genetic counselling training programs on an individual basis.

Not all institutions' courses in genetics or counselling meet the Board's requirements. All applicants are considered on their individual merits. Approval of a previous candidate's coursework by the Board does **NOT** set a precedent of guaranteed approval of such coursework for other applicants. Thus it is essential that all potential trainees seek course approval **prior** to coursework commencement by sending the Proposed Courses form to the Board (see page 15).

Both Part 1 and Part 2 candidates are required to report to the Board at least annually, on the anniversary of their first contact with the Board. This ensures that their course work selection, progress, and successful training completion may be facilitated and assessed by the Board. Submission deadlines for either Part 1 or Part 2 are the 31st of January and the 31st of July, each year. Late submissions will **not** be considered until the next biannual deadline.

It is preferable for candidates to complete Part 1 prior to commencing Part 2. Board approval of commencement of Part 2 may be considered prior to completion of Part 1, only after the candidate's employment in a genetic counselling role for one year. The Board may mandate that certain sections of the Part 1 checklist be completed prior to the approval for a candidate's commencement of Part 2. Once again, this is assessed on an individual basis.

The Board will recommend to the Council of the HGSA that a candidate be certified as a genetic counsellor only after successful completion of both Parts 1 and 2, and upon receipt of satisfactory genetics and counselling supervision reports. When a candidate submits the final case study longer than six months after the last supervision report(s), the Board, prior to the granting of certification, may request a final report(s).

E. TRAINING FOR COUNSELLORS IN THE AREA OF CANCER GENETICS

The field of genetics is making a significant contribution to the identification of families and individuals who may have an increased risk of developing certain forms of cancer. As more is discovered about the genetic mechanisms of familial cancer, the demand for services, which can provide information and support to such families, is growing.

Genetic counselling for familial cancer is offered through specialist familial cancer clinics or through genetics departments in major hospitals. However, demand is far outstripping resources and it is anticipated that there will be a growing need for well-trained and informed professionals in this field. Genetic counsellors are now recognized as important members of this team of professionals. The Board of Censors has, in consultation with both counsellors and clinical geneticists working in familial cancer, formulated a set of guidelines for the training and certification of these cancer genetic counsellors. The training program aims to be accessible, flexible and practical and will enable candidates to achieve a recognised certification in this specialised area. Due to limited training resources, it is based on the structure of the existing program for training in genetic counselling.

The requirements for Part 1 training, the theoretical component, are identical to those for general training in genetic counselling. The checklist for Part 1 appears on page 17 of this document.

Part 2 Cancer Genetics Certification will be gained after a minimum of one year's full time employment, (or equivalent in part time hours,) in a recognised familial cancer clinic or clinical unit providing these services. Candidates will need to have access to a full range of cancer genetics services to complete this section of the training and also submit 50 logbook cases and 10 long cases during Part 2. Reporting is required on a six monthly basis from both genetics and counselling supervisors, who monitor the candidate's progress. Guidelines for writing case studies, a pro forma for the logbook and details of supervision requirements can be found in Section 3 of this document.

If a person has completed certification in the area of cancer genetics and wishes to obtain certification in the general genetics field, there would be no further Part 1 study required. However, a further minimum eighteen months of full time work in a general genetics setting, submission of a further 50 non-cancer logbook cases, 15 further non-cancer long cases (maximum 5 cases per 6 months), and reports of both types of supervision are required.

To distinguish those who are training or have completed training in this field, a title similar to Associate Cancer Genetic Counsellor or Cancer Genetic Counsellor will be used.

SECTION 2: REQUIREMENTS FOR PART 1 OF CERTIFICATION IN GENETIC COUNSELLING

Part 1 of the training requires successful completion of courses in both genetics and counselling to attain the required levels of skills and knowledge in these areas.

A candidate may be given full or partial credit for Part 1 (Genetics) and/or Part 1 (Counselling) dependent upon the successful attainment of skill and knowledge in each area.

It is preferable for candidates to commence Part 2 following the completion of Part 1. However, commencement of Part 2 will be considered if candidates have had a minimum of 12 months full-time work. Completion of certain sections of the checklist for both counselling and genetics is essential prior to the commencement of Part 2, with the Board examining each case on its merits.

Where a candidate does not commence Part 2 upon the attainment of Part 1, the candidate may continue to provide to the Board documentation of an interest in the area on an annual basis. However such an application is optional and it is anticipated that those seeking employment as Genetic Counsellors will give an undertaking to work towards full certification.

A. GENETICS

Required areas of human genetics study are outlined in the checklist at the end of this document. Candidates are required to have gained sufficient genetics knowledge, such as the principles of inheritance, segregation analysis and genetic testing, to be able to understand, interpret and explain basic concepts and risk assessments to clients and families. An awareness of the social, legal and ethical implications of genetic testing and an understanding of the health care environment are also essential areas of knowledge for the genetic counsellor.

These areas of human genetics can be studied in a variety of ways. In some parts of Australia there are courses available which will satisfactorily cover all the areas listed. These courses are not required training for the genetics component of Part 1 but any candidate who satisfactorily completes one of these courses will be awarded Part 1 (Genetics). These courses are:

1. Human Genetics Theory (BIOL 345) (Macquarie University, Sydney, NSW). Prerequisites for this course may be necessary depending on a candidate's previous study. The recommended prerequisite is the Macquarie University Genetics Course 245. All aspects of the genetics checklist are not covered by this course. However, as the majority are, the rest can be supplemented by a supervised reading list that can be obtained from the Board

2. Genetics Units offered by Edith Cowan University:
   (i) Human Genetics (SCH 133)
   (ii) Medical Genetics (SCH 2233)
   N.B.: (i) is a prerequisite for (ii).

3. Graduate Diploma in Genetic Counselling or Masters in Genetic Counselliung, University of Melbourne, Melbourne, Victoria.

4. Graduate Diploma in Genetic Counselling, University of Newcastle, Newcastle, NSW.

5. Graduate Diploma in Genetic Counselling, Charles Sturt University, Wagga Wagga, NSW.

6. Graduate Diploma or Masters in Genetic Counselling, Griffith University, Nathan, Brisbane, Qld

This list is not exhaustive and there may be other courses that cover the areas listed in the checklist, which are not known to the members of the Board of Censors. As such courses are recognised and approved the list of courses will be updated.

In view of the wide variety of courses that a candidate can undertake, a checklist of course content has been developed as a means of objective comparison. Where one of the approved courses listed above has not been undertaken, the candidate is required to indicate to the Board on the checklist, the areas which have been covered. Completion of the checklist will guide the Board and the candidate in determining which areas of human genetics require further study or supplementation. **In the event that a chosen course does not meet all the requirements of the checklist, candidates may be given Board assistance by completing an approved supervised reading program.**

Approval for courses undertaken by candidates must be prospective unless a course was completed by a candidate prior to commencement of training as a genetic counsellor. Once approved, the Board expects the candidate to satisfactorily complete all the required assessments for the course(s) unless exemptions are preapproved by the Board and the institution.

The following forms, located on pages 15 - 24, are for use by applicants to the Board for Part 1 (Genetics):

1. **PROPOSED COURSES:** for use when candidates are proposing a course(s) of study in genetics. Where the course is not listed as approved, the candidate should discuss the checklist, which delineates the required knowledge, with the course coordinators to ensure that the course is suitable in whole or part. It is recognised that not all courses will cover all areas and thus a course may provide partial credit to Part 1 (Genetics). The use of the checklist will guide the candidate as to the areas of study that need to be pursued in order that all the required knowledge is achieved. It may be that the areas not covered in an available course can be addressed in some other manner such as a supervised reading program. Candidates are advised to note the areas of deficiency in the course (if any) and the Board will advise on the appropriate course(s) of action to facilitate the acquisition of the required knowledge.

2. **COMPLETED COURSES:** For use where courses have been completed prior to submission to the Board regarding Part 1 (Genetics). Where the course is not on the approved list, candidates should include a copy of the syllabus and copies of official results and certificates. For candidates who have completed an approved course, a copy of official results (academic record) should be included.

3. **GENETIC KNOWLEDGE CHECKLIST:** for use where the course either proposed or completed is not listed as approved. Please note that this list will be continually updated and distributed to candidates as the Board approves further courses. The course number that denotes the course listed in either the proposed or completed form is used in this checklist for efficiency.

The course coordinators should sign the checklist completed by the candidate to verify that the items are covered in the course.

B. COUNSELLING

Formal training for Part 1 (Counselling) requires candidates to have obtained a high level of skill and knowledge. The areas of counselling that are required to have been studied are outlined in the checklist at the end of this document.

There is no prescribed course for the attainment of these skills and knowledge in these areas. However, there are several courses that, if satisfactorily completed, will result in the award of Part 1 (Counselling). If a counselling course other than one incorporated within a Graduate Diploma is undertaken, all aspects of the counselling checklist may not be met. If a substantial proportion of the checklist will be covered, candidates undertaking one of these courses can expect to have to complete some parts of the checklist with a reading list as suggested by the Board. Candidates will also need to complete a practicum in a recognised genetic counselling setting. Please contact the Board for guidance if you intend to undertake one of the non-graduate diploma courses.

These courses include:

1. Institute of Counselling (2 years part-time), Sydney, NSW

2. Master of Social Science (Counselling), Edith Cowan University, Perth, WA. Completion of Stage 1 only of this course will satisfy training requirements.

3. Graduate Diploma in Health Counselling, The University of South Australia, Adelaide.

4. Advanced Diploma of Applied Science, the Australian College of Applied Psychology. (Offices are in NSW, phone 02 9211 2122 and Queensland but distance education is also offered. Also may be relevant where specific counselling skills are required, and a local course is not available, as various modules can be studied independently of the Advanced Diploma).

5. Graduate Diploma of Counselling, the Australian College of Applied Psychology. (Offices are in NSW, phone 02 9211 2122 and QLD but distance education is also offered. Also may be relevant where specific counselling skills are required, and a local course is not available, as various modules can be studied independently of the Graduate Diploma)

6. Master of Social Science (Counselling), University of South Australia. (This is a post-graduate course and careful selection of electives should be made).

7. Graduate Diploma in Counselling, Bachelor of Counselling and Master of Counselling, University of New England.

8. Graduate Diploma or Masters in Genetic Counselling, University of Melbourne, Melbourne, Victoria.

9. Graduate Diploma in Genetic Counselling, University of Newcastle, Newcastle, NSW

10. Graduate Diploma in Genetic Counselling, Charles Sturt University, Wagga Wagga, NSW

11. Graduate Diploma or Masters in Genetic Counselling, Griffith University, Nathan, Brisbane, Queensland.

12. Certificate in Counselling through the Wasley Institute, Mount Lawley, Western Australia. This is a two-year, part-time course.

This list contains only those counselling courses known to the members of the Board. As other courses are approved as meeting the requirements, the list will be updated.
Nevertheless, not all candidates will undertake these courses and the skills may also be obtained from several short courses. Where a candidate has not completed an approved course, in order for the Board to be able to ascertain that all the required areas of training in the development of the counselling skills has been covered, a checklist of course content has been developed. The candidate is required to complete the checklist indicating in which course and at what level the skill has been obtained. This will enable the candidate and the Board to objectively determine if a candidate has undertaken a course (or courses) that are comparable to those which have been approved. **In the event that a chosen course does not meet all the requirements of the checklist, candidates will be given assistance through the provision of an approved reading list.**

Application forms, located on pages 14, 15, 16 and 22, are intended for use by the candidates when applying to the Board for Part 1 (Counselling) and their use is described below:

1. PROPOSED COURSES: for use where candidates are proposing a course(s) of study in counselling. Where the course is not listed as approved, the candidate should discuss the checklist that delineates the required knowledge with the course coordinators to ensure that the course is suitable either wholly or partly. It is recognised that not all courses will cover all areas and thus a course may provide partial credit towards Part 1 (Counselling). The use of the checklist will guide the candidate as to the areas of study that need to be pursued in order that all the required knowledge is achieved. It may be that the areas not covered in an available course can be addressed in some other manner such as a supervised reading program.

Candidates are advised to note the areas of deficiency in the course (if any) and the Board will advise on the appropriate course(s) of action to facilitate the acquisition of the required knowledge.

2. COMPLETED COURSES: for use where courses have been completed prior to submission to the Board regarding Part 1 (Counselling). Where the course is not on the approved list, candidates should include a copy of the syllabus, and copies of official results and certificates. For candidates who have completed an approved course, a copy of official results (academic record) should be included.

3. COUNSELLING SKILLS CHECKLIST: for use where the course either proposed or completed is not listed as approved. Please note that this list will be continually updated and distributed to candidates as the Board approves further courses. The course number that denotes the course listed in either the proposed or completed form is used in this checklist for efficiency.

The course coordinators should sign the checklist completed by the candidate to verify the items are covered in the course.

C. GUIDELINES FOR READING COURSES

The preferred option for candidates for Part 1 of the training is participation in approved or suggested courses. However, it may be necessary for some candidates to complete reading courses. These can be worthwhile learning experiences and can be especially useful when there is no appropriate formal course available locally or when a local course requires supplementation.

In the area of genetics, reading courses are suitable. However, a reading course is not a suitable means to gain adequate counselling qualifications, unless it is being used to increase and bring up to date already existing proven skills and qualifications.

Proposed or past reading courses should be presented to the Board in the same way that other courses are proposed. Approval for proposed or past reading courses will be given on an **individual basis** i.e. it must not be assumed that Board approval for a colleague's reading course will automatically apply. The proposal/evidence of a completed course must include:

1. A description of how the reading course was/will be conducted. For example, how often the candidate and supervisor/teacher intend meeting.

2. Supervision: The name/s of the supervisor and their qualifications. The content of past or proposed supervision must be outlined with an explanation of how this supervision is aiming to incorporate the reading material into the practice of genetic counselling. The submission must include details of the date and length of time spent with the supervisor/teacher and the date that each reading was completed. However, the "length of time" spent with the supervisor is less important than the content of that supervision.

3. A list of the individual topics intended to be or which have been covered with evidence that the recommended reading list in the training guidelines has been consulted.

4. A bibliography (journal articles, texts etc) intended to be used for each topic to be submitted when the reading course is proposed as well as when the course has been completed and is being submitted.

5. A list of any other learning activity related to the topic (e.g. laboratory visit, assessment etc) that may supplement the reading course.

D. APPLICATION FEE FOR PART 1

The HGSA requires that its Boards of Censors be self-supporting. Thus fees are charged for Part 1 and Part 2 submissions to the Board of Censors in Genetic Counselling to fund the meetings and administrative costs incurred. Cheques **made payable to the HGSA** must accompany the initial applications for Part 1 and 2. A total of $440.00 is charged for HGSA Certification in Genetic Counselling, chargeable in the following manner:

PART 1 $110.00
Submission to the Board for approval of proposed courses or retrospective approval of previous courses undertaken as well as recognition of successful completion of approved courses. This fee covers all submissions until Part 1 is awarded for both genetics and counselling. No certificate is issued on completion of Part 1 training.

The remaining $330.00 is payable at the time of the initial submission for Part 2 (see page 80)

E. APPLICATION FOR PART 1

The following forms are to be used for applications to the HGSA Board of Censors for Certification in Genetic Counselling. Separate forms are to be used for Part 1 and 2. In most cases, a candidate will apply for Part 1 prior to applying for Part 2.

The closing dates for submission each year are January 31 and July 31. Whenever a submission is made to the Board a total of four (4) copies of the submission should be sent to the Secretary of the Board of Censors for Genetic Counselling. Please note that applications will not be accepted if they are not received by the due date and do not include four (4) copies of every page including any covering letter.

Candidates who are proposing to undertake, or who have already completed, an approved course should complete the course details on the accompanying form. A copy of their acaedemic transcript should be included with the application.

For those candidates who are proposing a course(s) in either counselling or genetics which is not listed as approved, the course details must be accompanied by completion of the checklist of course content described in Section 2. It is important to provide course details cumulatively so that previously completed courses are also shown.

Where a candidate proposes a course of study in either or both genetics and counselling that meets the Board's requirements, the Board will advise the candidate that successful completion of that course will result in the award of Part 1 in either or both genetics and counselling. The Board may award Part 1 (Genetics) and Part 1 (Counselling) separately or together, dependent upon the candidate satisfying the Board that the required knowledge has been covered in the various courses. A letter is issued to the candidate from the Board.

No certificate is issued on completion of Part 1.

APPLICATION FOR HGSA CERTIFICATION IN
GENETIC COUNSELLING

PART 1

NAME:____

ADDRESS:____

____

____

TELEPHONE:__________________________ FAX: _______________________

DATE OF BIRTH:_______________________

CURRENT EMPLOYER:____

ADDRESS:

____

____

____

TELEPHONE:__________________________

INITIAL SUBMISSION DATE:

____

DATE OF THIS SUBMISSION:

____

HAVE YOU INCLUDED FOUR (4) COPIES OF EVERY SHEET YOU ARE SENDING WITH THIS APPLICATION (INCLUDING THIS PAGE)?

IF IT IS YOUR INTENTION TO COMMENCE PART 2, PLEASE COMPLETE THE APPLICATION FORM ON PAGE 70

PROPOSED COURSES

*COURSE NO. (1,2,3, etc) (to be used with checklist)	COURSE TITLE	INSTITUTION/ ORGANISATION	ASSESSMENT METHOD	DURATION OF COURSE	REFERENCES USED (Attach list if necessary)
1					
2					
3					
4					
5					

COMPLETED COURSES
(Complete checklist if not an approved course)

*COURSE NO. (1,2,3, etc) (to be used with checklist)	COURSE TITLE	INSTITUTION/ ORGANISATION	ASSESSMENT METHOD/RESULT	DURATION OF COURSE	REFERENCES USED (Attach list if necessary)
1					
2					
3					
4					
5					

GENETIC KNOWLEDGE CHECKLIST

AREA OF HUMAN GENETICS	ACCOMPLISHED YES/NO/IN PART	COURSE TITLE *use no. from proposed/ completed course details	NUMBER OF HOURS ON TOPIC	FORM OF LEARNING IN THIS AREA e.g. lectures, workshops, practical classes, seminars
CHROMOSOMES				
organisation				
structure				
mitosis				
meiosis				
cell cycle control				
GENES				
structure of DNA				
definition				
structure				
introns, exons				
transcription				
translation				
protein structure				
control				
PATTERNS OF INHERITANCE				
Mendelian				
multifactorial				
segregation analysis				
mitochondrial				
uniparental disomy				
imprinting				
trinucleotide repeats				
gonadal mosaicism				

GENETIC KNOWLEDGE CHECKLIST

AREA OF HUMAN GENETICS	ACCOMPLISHED YES/NO/IN PART	COURSE TITLE *use no. from proposed/ completed course details	NUMBER OF HOURS ON TOPIC	FORM OF LEARNING IN THIS AREA e.g. lectures, workshops, practical classes, seminars
CYTOGENETICS				
banding				
numerical abnormalities				
structural abnormalities				
mosaicism				
sex determination				
chromosomal inheritance				
molecular techniques				
F.I.S.H.				
laboratory experience and interpretation of laboratory reports				
PRENATAL DIAGNOSIS				
indications				
screening				
procedures diagnosis				
risks, consequences				
applications				
1st and 2nd trimester screening				
nuchal translucency				
preimplantation				
DYSMORPHOLOGY				
Use of L.D.D; O.S.S.U.M; P.O.S.S.U.M; L.N.D				
concept of syndromes				
examples				
BIOCHEMICAL GENETICS				
categories of metabolic disease				
inborn errors of metabolism				
storage disorders (eg MPS, Gaucher)				

GENETIC KNOWLEDGE CHECKLIST

AREA OF HUMAN GENETICS	ACCOMPLISHED YES/NO/IN PART	COURSE TITLE *use no. from proposed/ completed course details	NUMBER OF HOURS ON TOPIC	FORM OF LEARNING IN THIS AREA e.g. lectures, workshops, practical classes, seminars
disorders of carbohydrate, protein and fat metabolism (eg galctosaemia)				
PKU, urea cycle disorders (eg MCAD)				
mitochondrial disorders (eg MELAS, MERRF, Leigh Disease)				
prenatal diagnosis for metabolic disorders				
MOLECULAR GENETICS				
techniques: RFLP's, PCR, SSCP, blotting, heteroduplex, protein truncation, tandem repeats, gene mapping, positional cloning, hybridization chip				
recombinant DNA and applications in medicine				
diagnosis by linkage studies				
diagnosis by direct gene analysis				
laboratory experience and interpretation of laboratory reports				
MUTATIONS				
role of mutation in evolution (good genes)				
concept in disease				
types of mutations				
interaction with environment				
mutation frequency				
BIOSTATISTICS				
basic principles				
linkage analysis				

GENETIC KNOWLEDGE CHECKLIST

AREA OF HUMAN GENETICS	ACCOMPLISHED YES/NO/IN PART	COURSE TITLE *use no. from proposed/ completed course details	NUMBER OF HOURS ON TOPIC	FORM OF LEARNING IN THIS AREA e.g. lectures, workshops, practical classes, seminars
lod scores				
Bayesian analysis				
risk calculations				
calculations for consanguinity				
CANCER GENETICS				
oncogenes, proto-oncogenes, tumour, suppressor genes, mismatch repair genes				
Mendelian cancers				
screening and testing for familial cancers, eg breast, ovarian, bowel, prostate and rarer cancers, eg retinoblastoma, VHL, MEN, Li Fraumeni, Wilms tumour				
awareness of current guidelines for testing				
EMBRYOLOGY				
mechanisms of teratogenesis				
normal development stages				
malformations				
deformations				
disruptions				
dysplasias				
common teratogenic agents, eg medical and non-medical drugs; vitamin A; alcohol				
role of folate in neural tube defects				
familiarity with a teratology database eg. TERIS; REPROTEXT; Shepard's catalogue				

GENETIC KNOWLEDGE CHECKLIST

AREA OF HUMAN GENETICS	ACCOMPLISHED YES/NO/IN PART	COURSE TITLE *use no. from proposed/ completed course details	NUMBER OF HOURS ON TOPIC	FORM OF LEARNING IN THIS AREA e.g. lectures, workshops, practical classes, seminars
HEALTH CARE SYSTEM				
identify community resources, educational resources and databases				
understand principles of ‘networking’				
organisation				
genetics services				
economic aspects				
screening principles - newborn screening				
HGSA guidelines for genetic testing and prenatal diagnosis				
LEGAL/ETHICAL/SOCIAL APSECTS				
clinical genetics				
genetic counsellors Code of Conduct				
HGSA ethical guidelines				
confidentiality				
Human Genome Project				
POPULATION GENETICS				
ethnic differences				
founder effects				
gene and carrier frequencies				
TREATMENT IN GENETIC DISEASE				
principles of genetic engineering				
gene therapy techniques - limitations/problems				
enzyme replacement				
cloning				

COUNSELLING SKILLS CHECKLIST

SKILL	**ACCOMPLISHED YES/NO/IN PART**	**COURSE TITLE *use no. from proposed/ completed course details**	**NUMBER OF HOURS ON TOPIC**	**FORM OF LEARNING IN THIS AREA e.g. lectures, role play, workshops, seminars**
DEVELOPMENTAL STAGES AND THEORIES OF HUMAN BEHAVIOUR				
Normal stages of development				
Psycopathology				
Theories of development - Freud; Erikson; Piaget				
Theories of human behaviour - physiological; psychoanalytic; behavioural; cognitive; humanistic				
GRIEF				
Grief and genetic disorders				
The impact of genetic disorders on idividuals and families				
Stages				
Techniques of counselling				
SYSTEMS				
Systems theory				
The family role and systems				
The health care setting as a system				
Multidisciplinary teamwork				
Support groups				
MULTICULTURAL COUNSELLING				
Multicultural resources within the health system				
Other cultures				
Other religions				
Using interpreters				

COUNSELLING SKILLS CHECKLIST

SKILL	ACCOMPLISHED YES/NO/IN PART	COURSE TITLE *use no. from proposed/ completed course details	NUMBER OF HOURS ON TOPIC	FORM OF LEARNING IN THIS AREA e.g. lectures, role play, workshops, seminars
INTERVIEW TECHNIQUES				
Family interviewing				
The grieving client/family				
Giving "bad news" e.g. the diagnosis				
Working with the deaf, visually impaired				
Working with people with limited understanding, eg children and the intellectually disabled				
COUNSELLING AND INTERVIEW SKILLS				
Open-ended questions				
Sensitive questioning				
Reflection				
Active listening				
Establishing empathy				
Acknowledging feelings				
Ventilation				
Non-verbal behaviour				
Communication blocks				
Defense mechanisms				
Anger				
Generalisation				
Giving feedback				
Setting goals				
Confrontation				
Interpretation				
Confidentiality				

COUNSELLING SKILLS CHECKLIST

DECISION MAKING				
Factors involved in the decision making process				
The counsellor's role in the decision making process				
Non-directiveness				
GENETIC COUNSELLING IN PRACTICE				
Intake procedures				
Assessing client needs and expectations				
The counsellor's role in the interdisciplinary team				
The autonomous counsellor (eg outreach)				
Accurate record taking				
Recording family pedigree				
Familiarity with computerised pedigree program eg Cyrillic				
Respecting client confidentiality in the workplace				
Supervised clinical placement in a clinical genetics unit (minimum 2 weeks)				
The burden of disease illustrated by common genetic conditions such as Fragile X, Down Syndrome, HD etc. Consider using support group members				
Differences between clinic consultations and home visits				

SECTION 3: REQUIREMENTS FOR PART 2 CERTIFICATION IN GENETIC COUNSELLING

In most cases a candidate will have completed Part 1 of their training prior to the commencement of Part 2. Training in Part 2 requires employment in, or attachment to, a clinical genetics unit in order that the theory gained in genetics and counselling can be applied to the practice of genetic counselling.

It is recommended that candidates inform the Board of their intention to commence Part 2 by completing the application from on page 73. This includes informing the Board hours of employment and that appropriate genetics and counselling supervision is in place.

A minimum of 2 years **full time equivalent** is required for documentation of Part 2 training, dated from the time at which the first log book entry of a genetic counselling case is made. Thus, while observing a genetic counselling session provides excellent and essential background and should be listed in the continuing education section of the documentation, these cases cannot be included as an entry in the logbook. In most circumstances, therefore, a candidate will not be able to commence the log book and case studies documentation of Part 2 training until some time after he/she has been employed in a clinical genetics unit.

Under some circumstances the Board will approve the commencement of Part 2 prior to the completion of, or concurrent with, Part 1. Candidates will need to have completed a substantial proportion of their Part 1 training and have worked the equivalent of at least one full time year in an appropriate setting. Such applications to the Board will be considered on an individual basis.

Where a candidate is employed in, or attached to, a clinical genetics unit part-time, a period of two days per week in Part 2 training is considered by the Board to be the minimum.

Documentation of the training must be submitted to the Board of Censors at least once annually on the anniversary of their first contact with the Board. However, applications may be made to the Board at both submission dates. Prospective approval of a training program and retrospective recognition of training will be given by the Board in reply to each submission.

A LOG BOOK

It is considered good work practice and recommended by the Board that candidates keep a record of all those genetic counselling cases in which he/she has actively participated and been supervised. Every case in which the candidate has actively participated should be documented **in a format of his/her own choosing such as a workbook.** The cases can include face-to-face and telephone counselling, follow-up visits and home visit covering the categories listed below. Cases where the candidate has only observed a genetic counselling session should not be included. It is recommended that the genetic or counselling supervisor sign this workbook at regular intervals, preferably monthly, confirming that the candidate has actively participated in the cases. Long cases should not be drawn from the logbook. Where a candidate submits a case in their logbook and then chooses to write it up as a long case, they should add another new case to their next logbook submission.

Trainee genetic counsellors have two classes of supervisors, i.e. "genetics" and "counselling" and may have more than one supervisor in each of these areas at different times. The workbook only needs to be signed by a single supervisor although this should be a supervisor who supervised the case. Regular review of the workbook with supervisors will assist in the choice of future cases, to cover any deficient areas.

A sample of these cases are to be submitted in the form of a **log book** which will be used as part of the Board' s assessment of the breadth of the candidate's experience and involvement.

LOG BOOK FOR SUBMISSION TO THE BOARD FOR GENERAL GENETICS CERTIFICATION

A minimum of 50 cases selected from the workbook must be submitted to the Board each year of Part 2 training. These should be presented in the format, and under the category headings, described below. It is strongly recommended that the logbook be typed. Only cases in which the candidate has actively participated should be included in the logbook. Clients should not be identified by name in the logbook.

Where a candidate is training full-time, the entire 50 cases should be presented in one submission. Where a candidate is training part-time, the number of cases required per year should be pro-rata, determined by the proportion of time spent in training.

The supervisor is required to sign each page of the log book that is submitted to the Board, verifying that the cases listed were included in the workbook used by the candidate as a continuing record of cases.

After 100 logbook cases have been submitted over at least a two year period the candidate can request that the Board determine whether these 100 log book cases cover a sufficient range of genetic conditions and types of inheritance. **IF THIS IS THE CASE THE BOARD WILL INFORM THE CANDIDATE THAT NO FURTHER LOGBOOK CASES ARE REQUIRED.**

The cases should cover pregnancy, childhood and adult conditions. Cases should be listed under the following categories, **with each category on a separate page:**

1. **Grief/loss** e.g. after pregnancy loss, neonatal or childhood death, or in response to an abnormal newborn or to a newly made diagnosis in an individual or family (may include adult onset disorders).

2. **Presentation of options/decision making** e.g. reproductive options, options in regard to prenatal diagnosis, predictive test decisions in childhood and adult onset disorders.

3. **Termination of pregnancy** e.g. counselling couples who are making a decision about whether or not to continue a pregnancy.

4. **Provision and explanation of tests, their risks and results** e.g. explaining CVS and amniocentesis, DNA tests, chromosome tests, maternal serum screening, neonatal screening.

5. **Patterns of inheritance** e.g. recessive, dominant, X-linked, chromosomal disorders, imprinting, multifactorial, mitochondrial in childhood and adult onset disorders.

6. **Description of a phenotype** e.g. a single gene, chromosome or multifactorial disorder, some of which should involve malformations, not cancer (major or minor) and mental retardation in newborns, children and adults.

7. **Family function** e.g. denial, blame, communication difficulties, marital problems, and family members with different attitudes to a particular issue.

8. **Ethical, legal, confidentiality and management issues** e.g. enrolment into research projects; the role of registers and implications of inclusion on a register; confidentiality issues; insurance implications, testing of children etc.

NOTE: It is recognised that any given case may involve counselling issues from more than one category. You can choose which category the case should come under and list in the section headed "other issues addressed", any other areas covered. The same case cannot be entered into different categories. The same case cannot be entered in different categories. For example, a case of prenatal diagnosis of a fetus with trisomy 21 could come under the category of grief/loss. In the column "Issues addressed by counsellor" tell us your role in the consultation and what you discussed with the client. Under "other issues addressed", briefly state what issues from the other categories were addressed in the consultation, e.g. "family function", which might include such issues as sibling relationships, denial of disease by partner etc.

For each case there should be:

1. Case (Client identifier e.g. initials, case number)
2. Supervisor's name
3. Date seen
4. Diagnosis
5. Contribution of the associate genetic counsellor to the counselling e.g. preclinical assessment with documentation of the pedigree, discussion of inheritance pattern during the consultation, follow-up phone call
6. Other counselling issues relevant to the case
7. Supervisor's signature

LOG BOOK FOR SUBMISSION TO THE BOARD FOR CANCER GENETICS CERTIFICATION

A minimum of **50** cases selected from the workbook must be submitted to the Board each year of Part 2 training. These should be presented in the format, and under the category headings, described below. Only cases in which the candidate has actively participated should be included in the logbook.

Where a candidate is training full-time, 25 cases should be presented in two submissions. Where a candidate is training part-time, the number of cases required per year should be pro-rata, determined by the proportion of time spent in training. The supervisor is required to sign each page of the log book that is submitted to the Board, verifying that the cases listed were included in the workbook used by the candidate as a continuing record of cases.

Clients should not be identified by name. It is strongly recommended that logbooks be typed.

The cases should be listed under the following categories, **with each category on a separate page:**

1. **Grief/loss** e.g. loss of self image due to confirmation of carrier status, diagnosis of cancer or surgery, loss of relatives to cancer

2. **Presentation of options/decision making** e.g. reproductive options, predictive test decisions, ongoing management options (surveillance, prophylactic surgery). Although it is usually not the role of the associate genetic counsellor to make recommendations regarding ongoing management, they may assist clients in clarifying options and decision making.

3. **Pregnancy related issues** e.g. testing in pregnancy, associated risks, termination etc. Although this will not be as commonly encountered as with general genetic counselling, candidates should endeavour to put some entries into this category.

4. **Provision and explanation of test results** including DNA testing, age related risks, implications for other family members, etc.

5. **Family function** e.g. denial, blame, communication difficulties, marital problems, communicating important information to other family members.

6. **Genetics of cancer disorders** eg pathophysiology of cancer, inheritance patterns; significance of different genes involved; types of cancers associated with different genes;

7. **Ethical, legal, confidentiality and management issues** e.g. enrolment into research projects; the role of registers and implications of inclusion on a register; confidentiality issues; insurance implications, testing of children etc.

NOTE: It is recognised that any given case may involve counselling issues from more than one category. You can choose which category the case should come under and list in the section headed “other issues addressed”, the other categories covered. For example, if you choose to list your client under the category labelled “provision and explanation of test results”, you would explain all the counselling issues covered by you for that client in the column headed "Issues addressed by Counsellor". Under “other issues addressed”, briefly state what issues from the other categories were addressed, e.g. “family function”, which might include such issues as sibling relationships, denial of disease by partner etc.

For each case there should be:

1. Client identifier e.g. initials, case number
2. Supervisor's name
3. Date seen
4. Diagnosis
5. Contribution of trainee genetic counsellor to the counselling e.g. preclinical assessment with documentation of the pedigree, discussion of inheritance pattern during the consultation, follow-up phone call
6. Other counselling issues relevant to the case
7. Supervisor's signature

GENETIC COUNSELLING CERTIFICATION

LOG BOOK

Category: Termination of pregnancy

Case	Supervisor	Diagnosis	Counsellor's contribution	Other counselling issues	Date seen
27159	AB MS	Neural tube defect	Emergency phone contact from mother following 18 week U/S diagnosing condition in foetus and told had only 1 week to decide what to do. Issues of giving and hearing bad news. Arrange same day appt to meet with recently separated couple. Exploration of feelings re diagnosis, options re TOP. 1st child with galactosaemia and recently made decision made not to harm foetus with any tests. Father recently expressed strong views against abortions 'killing babies'. Facilitate and provide opportunity to consider all outcomes and impact of each, allowing resolution re decision. Support re decision.	Religious beliefs Shock and disbelief that this had happened. Unplanned pregnancy.	March 2000

GENETIC COUNSELLING CERTIFICATION

LOG BOOK

Category: Grief and loss

Case	Supervisor	Diagnosis	Counsellor's contribution	Other counselling issues	Date seen
28247	AB MS	Adult untreated PKU	Co session with Dr. and x3 F/U telephone calls with older sister who initiated contact after local GP diagnosed condition. Discussion re PKU, advent of NBS program, current management and favourable outcome for those detected and treated early. Acknowledged sisters distress, and anger that condition not diagnosed and thus treated. Identify and explore sister's grief over missed opportunities, loss of normal brother, painful childhood memories re witnessing parent's distress at brother's 'mental retardation'. Discuss AR inheritance Liaison with Social Worker for ongoing grief issues for sister.	Sister's need 'to be needed' and help brother by cooking PKU foods. Sister's loneliness and isolation	July 1999

Category: Presentation of options / decision making 12 cases

CASE	SUPERVISOR DATE SEEN	DIAGNOSIS	COUNSELLORS CONTRIBUTION	COUNSELLING ISSUES
22436 SC	RJMG RT 19/1/00	FAP predictive testing (50%) risk in a 35 year old man	▪ Pre-clinic intake ▪ Liaison with FAP registrar to verify family mutation ▪ 1 x face to face counselling session ▪ numerous follow up phone calls to GP and consultand regarding follow up treatment after consultand received positive gene test result ▪ provision of written information to consultand and GP ▪ Liaison with gastroenterologist and medical geneticist regarding appropriate medical management	▪ Family discord ▪ Non-compliance – failed to attend first appointment and then didn't attend results session – result given by GP ▪ Unwillingness to discuss testing openly, just wanted test done ▪ Discussion re pros and cons of testing ▪ Boundaries: is it the responsibility of the GC to make sure that the consultand makes it to the gastroenterologist/surgeon?
22081 BR	MD 2/3/00	Unverified family history of haemophilia in maternal uncle – determination of carrier risk in a 30 yr old woman	▪ Medical and genetic aspects of haemophilia discussed ▪ Pre-clinic intake and attempt to verify family history – no records to confirm a diagnosis in deceased maternal uncle ▪ Discussion of both types of haemophilia, X linked inheritance ▪ Discussion of coagulation studies (FVII, FXI, FV antigen), inversion test and carrier risk calculation ▪ Normal coagulation studies, no inversion, low carrier risk given. Risk generated using Bayes theorem which took into consideration family history and results of tests ▪ 1 x face to face counselling, 2 x follow up phone calls	▪ No verified family history, therefore the information given was only accurate only if the diagnosis existed ▪ Risks and lack of prenatal testing options ▪ Very little communication in family
21818 CH	RJMG 17/3/00	Predictive testing for HNPCC (50% risk) in a 42 yr old woman	▪ Pre-clinic intake – pedigree details verified, brief discussion of her understanding of HNPCC and genetic testing, current surveillance noted ▪ Predictive test counselling, face to face and by phone (3 sessions total) ▪ Disclosure and follow up phone call ▪ Provision of written information about HNPCC and CRC prevention	▪ Decision making for the future ▪ Lack of family communication regarding identification of mutation ▪ Impact of cancer on extended family ▪ Impact of positive and negative result on immediate family and work ▪ Impact of disclosing results to adolescent children

Category: Pregnancy tests and their risks 3 cases

CASE	SUPERVISOR DATE SEEN	DIAGNOSIS	COUNSELLORS CONTRIBUTION	COUNSELLING ISSUES
30691	MD 20/6/00	FHx of CF – carrier testing in a 31 yr. old woman contemplating her first pregnancy	▪ Pre-clinic intake and documentation of pedigree ▪ 2 x face to face counselling sessions ▪ several follow up phone calls ▪ verification of family mutation not possible as affected family member deceased and lived in Ireland before gene testing available ▪ AR inheritance explained, carrier risk calculated, testing organised ▪ consultand turned out to be carrier. Her partner was tested – also a carrier ▪ Reproductive options explained – will opt for CVS ▪ CVS and risks explained in detail ▪ Mechanism put in place to access services when tyhey become pregnant	▪ Shock at both being carriers ▪ Loss of excitement of pregnancy, now have to consider testing ▪ Non disclosure of carrier risk to husband's brother ▪ Natural history of CF
27021 LR	RJMG/RS RT 3/8/00	36 yr old woman who has fragile X full mutation – contemplating a pregnancy	▪ 4 x face to face counselling sessions ▪ Sex linked inheritance, triplet repeats and risks in pregnancy explained ▪ Exploration of family history and own feelings about if she thinks she is affected at all ▪ Long discussion re reproductive options. Initially interested in PGD, but then decided on CVS. TOP discussed. ▪ Referral to prenatal clinic to familiarise herself with the service. I attended this appointment with her ▪ Arranged contact with another woman who has had Fragile X prenatal.	▪ Female foetus with full mutation – to terminate or not – very difficult decision and still resolving – what does this say about herself ▪ The emotional and psychological impact of termination of pregnancy if she were to have one ▪ Her personal experience with Fragile X syndrome in her brother and nephews – she would definitely terminate a boy

B. CASE STUDIES – (Long Cases)

Each candidate is required to submit twenty annotated long cases in which he/she has played a major role. The cases should illustrate the breadth of experience gained by the candidate during the Part 2 minimum 2-year full time training period, or its part time equivalent. Some cases may be longer than others and often a shorter case involving only one client face to face contact can be just as effective in illustrating the candidate's insights and abilities, as a longer case where multiple client contacts took place. If submitting two or more cases with similarities, e.g. two cases of maternal serum testing, the candidate must demonstrate different counselling issues and approaches in each case. The Board will determine for each candidate how many similar cases out of a total of 20 can be submitted.

If you work in a speciality area, please inform the Board, who will communicate with you the number of cases you may submit from that area.

<u>What is the Board looking for as a candidate progresses through Part 2?</u>

As a candidate progresses through Part 2 the Board is looking at their professional development. It is expected that as the counsellor progresses through Part 2 they will demonstrate a professional maturation and this will be reflected in the breadth of skills the counsellor is able to utilise in their practice, the depth of case analysis, and a greater level of self awareness. The Board expects that a candidate will demonstrate the utilisation of a greater skills base from which they practice, and a greater depth of theoretical case analysis in the final 10 long cases as compared to the initial 10.

A candidate for Part 2 may submit one to five case studies (or draft forms) for consideration by the Board biannually. **<u>The Board will not accept more than five (5) case studies per six month period.</u>** This will enable candidates to pace their progress, receive adequate feedback on their cases and make the workload for Board members more manageable.

Although documenting understanding of each case's genetic information is important, **the prime emphasis should be the candidate's demonstration of the counselling issues relevant to each case.**

Each case study must include details of the nature and content of supervision received (must pertain to the specifics of the case).

As a guide, the genetics discussion should be 300 – 500 words (minimum). Discussion of counselling issues should be 400 – 600 words (minimum). Candidates may choose to write more than this.

Case studies submitted in the form of a poster presentation do not meet the requirements of a long case as they provide insufficient scope for a discussion of counselling issues. However such poster presentations may be adapted to the required submission format.

Process of review of Part 2 submissions: two Board members independently review a candidate's Part 2 submission. Prior to the Board teleconference, the reviewers discuss the candidates' submission and a summary is presented at the teleconference where all Board members are present. The Board aims to maintain one reviewer who is consistent during the candidate's progress through Part 2 and allocate a new reviewer each submission.

Following the teleconference a letter is sent to the candidate with feedback about their submission. The Board may request a candidate resubmit parts of or whole cases.

The following case studies on pages 40 - 60 illustrate acceptable formats. These formats are only suggestions and others may be used, as long as all required sections are included

REFERENCING

Reference citations are required within the text of the case studies, as opposed to the provision of a bibliography or reading list. Referencing is required where readings were used to support all non-original concepts and ideas discussed in the text.

Examples of appropriate referencing systems include:

1. Alphabetical Referencing (preferable and easier to manage):
All references should be cited in the body of the text using, in brackets, the author's surname and the year of publication after the statement derived from his/her work, eg. most patients have expectations of counselling ……. (Smith, 1985). If there are several authors the first name is used followed by et al (eg. Jones et al, 1994). All the references are then listed under the title "References" in alphabetical order, at the end of the case study.

2. Numerical Referencing:
All references are cited in the body of the text using sequential numbers, ie. the first reference is (1) etc. These references are listed at the end of the case study in the numerical order in which they appear in the text (not in alphabetical order).

The purpose of listing references is so the reader can clarify a point or find more information on a topic of interest. The reader, therefore, must easily be able to find the reference material.

There is a difference between a Reference List and a Bibliography. The former refers to material that is actually cited and used in the discussion, whereas the latter (generally shorter) is material that is read during the preparation of the paper, but is not actually used as a source of information in the discussion. A bibliography is not necessary for the long case studies.

Where the reference is a book, the specific pages or chapters should be specified in the reference list, rather than just the title. References should appear in the list as follows:

For a journal article:
Cohen MM, Gorlin RJ. Pseudo-trisomy 13 syndrome. *Am J Med Genet* 1993; 39: 332-335.
If there are many authors the first 2 can be listed followed by et al.

For a book:
Gardner RJM, Sutherland GR. *Chromosome Abnormalities and Genetic Counselling.* Oxford, Oxford University Press, 2nd ed. 1996. Chap. 22: 91-93.
If different sections of the book are referenced throughout the long case, this is best managed by listing the chapter and pages in the body of the text, ie. (Winter et al, 1997, Chap 4:35-39) and the same book referenced later in the text (Winter et al, 1997, Chap 7: 87-92), with just the book details in the list of references at the end of the case.

For edited books with multiple chapter authors:
Djurdjinovic L. Psychosocial Counselling. In : Baker D, Schuette JL, Uhlmann WR (Eds)
A Guide to Genetic Counselling. New York, Wiley-Liss. 1998, p127-162.

For a conference abstract:
Ross M, Henry A. *Newborn screening and cascade testing for cystic fibrosis: an evaluation of the genetic counselling service over the past 10 years*. Human Genetics Society of Australasia Annual Scientific Meeting. Program and Abstract booklet. 2001: 26

For a personal communication:
If you wish to refer to a personal communication with an expert named, for example, Murray, the words J.Murray, personal communication, 2001, should appear in brackets in the text (not in the reference list) after the statement attributed to Murray.

Direct Referencing (includes Website referencing)

It is important that statements which quote the work of others are **correctly attributed to the original author(s).** Thus quoting review articles and Internet resources such as Geneclinics and OMIM is inappropriate as these sources summarise the work of the original authors. They are not the original articles.

If you quote from published material you must do so exactly, even to the repetition of the original author's syntax, punctuation and spelling. References must be accurate and complete to enable reviewers to follow up on sources.

Online publications are acceptable if they are original work. An example of referencing for electronic publications is presented below and can be found at the following web site http://www.columbia.edu/cu/cup/cgos/idx_basic.html.

Electronic Publications and Online Databases

List the author's name, last name first (if known); the title of the article, in quotation marks; and the title of the software publication, in italics. Next, list any version or edition numbers or other identifying information, the series name (if applicable), and the date of publication. Finally, cite the name of the database (if applicable) and the name of the online service--both in italics--or the Internet protocol and address, any other publication information, the directory path followed (if applicable), and, in parentheses, the date accessed.

> Christopher, Warren. "Working to Ensure a Secure and Comprehensive Peace in the Middle East." U.S. Dept. of State Dispatch 7:14, 1 Apr. 1996. *FastDoc. OCLC.* File #9606273898 (12 Aug. 1996).

GUIDELINES FOR DOCUMENTING HISTORY EITHER THROUGH THE NARRATIVE OR THE PEDIGREE

The taking and documentation of the family history is an essential and fundamental skill of genetic counselors. In addition to recording the relationships and health of at least three generations, a thorough history includes information that may also contribute to the counseling interaction and later management of the family/individual. The pedigree alone is therefore an abbreviated notation of many of the useful aspects of a family history.

INFORMATION TO BE INCLUDED IN THE PEDIGREE

It is vital to become familiar and use proper internationally recognized pedigree symbols. This allows others to interpret your findings, not only over time, but also over distance (i.e. in international journals or in poster presentations where the pedigree should be self-explanatory.) Below is an outline of the basic parts of a pedigree. You are encouraged to obtain more details through reading "Recommendations for Standardized Human Pedigree Nomenclature" *Journal of Genetic Counseling* 4(4) Dec 1995 and The Practical Guide to the Genetic Family History, by Robin Bennett, Wiley-Liss, New York, 1999. It is strongly advised that pedigrees be reviewed with either of your supervisors or your state Board representative prior to submission to avoid requests by the Board for pedigree revisions and resubmission.

1. Ethnic and Cultural background

The ethnic background comprises the racial, national, geographic and religious origins of the person, i.e. Irish Catholic, Ashkenazi Jew, Afrikaans, Turkish Cypriot, Hmong, etc. Differences in gene frequencies exist among races and persons of different national origins and thus this information may assist diagnosticians in their assessments. Special note- unless an individual is of Aboriginal or Torres Strait Islander descent (and noted as such), he/she would not ethnically be considered "Australian" for genetic purposes. (The same is true for other countries with multicultural populations, such as Canada and the United States.) Even if the families have been in Australia for many generations, it is important to obtain the ethnic descent, even if it is only noted as their geographic and/or religious origin, i.e. United Kingdom, French, African. A detailed and accurate ethnicity is vital, since many DNA mutation panels are chosen dependent on the provided ethnic origin of the person.

Other cultural background elements which may influence the session and outcome, and thus should be stated in the narrative, include the amount of time the individual/family has been in the current location, the language spoken at home, the literacy/education level and current/former occupations.

2. Consanguinity

Consanguinity should be noted in the narrative as well as made clear in the pedigree. It is important to remember that terminology (i.e. second cousins vs. first cousins once removed, half sibs vs. step sibs) used by the public may not be the same as those in genetic counseling. Asking and documenting specific information as to through whom or how two persons are related assures this accurately, and resolves conflicting information.

3. Reproductive history

Reproductive histories of the consultand and their extended family shed light on conditions that may result in pregnancy or neonatal lethality, sex biases, or sub-fertility. Noting, if possible, the timing, number, and sex of such losses is important, as well as any proven or suggested explanations (i.e. chromosomal studies, maternal illness, cord accidents, etc).

- **Freehand vs computerized pedigrees**

Free hand drawn pedigrees are perfectly acceptable, as long as they are neat and include the required information. Programs, such as Cyrillic or Progeny, may be used by applicants; however, these should be used noting that these programs often have differently formatted automatic numbering systems and symbols which may be more appropriate for research than clinical purposes. It is important to have proper training in the usage of such programs so that the numbering and key with acceptable clinical formatting is used in your presentations. <u>Pedigrees submitted where incorrect use of numbering systems and symbol designations are noted will be asked to be redone.</u>

- **Conventional symbols**

Current conventions apply the use of the circle, square, and diamond symbols and their connecting vertical and horizontal lines to provide the family members and the relationships between them. When using other symbols to designate adoptions, pregnancies, fetal losses, (qualifying spontaneous or elective), as well as stillbirths, these must be designated in the pedigree key or legend, since these symbols still vary greatly.

- **Alignment of generations**

The symbols of each generation should be placed on the same horizontal line. The only agreeable exception is reserved for individuals of different or overlapping generations, who are traditionally placed in their older partner's generation and not in their own sibship's level. When faced with sibships from multiple matings, the pedigree should be extended (beyond one page if necessary) to properly align the generations and decrease the possibility of confusion by the reader.

- **Designation of genetic traits**

An individual affected by a known condition usually has their symbol filled in solid or as designated in the key. If more than one trait in a pedigree is being considered simultaneously, the symbol can be divided into quadrants or halves and their meanings reflected in the key. A common mistake is the use of markings that mask one another or over-lap another symbols' trait designation. (i.e.- an upper right quad to mean be breast cancer in one person and the whole right side to mean CF carrier for another person in the same pedigree.) The same mistake can happen when a solid fill might cover a thatched fill of the same quadrant or half of symbol. Another note, the dot in the center of an individual's symbol is usually reserved to indicate either a carrier of an x-linked trait or a balanced chromosomal rearrangement. It is discouraged and not recommended for recessive traits due to this traditional use and understanding.

- **Proband vs consultand**

Many applicants are confused with these two terms. The proband is the person/pregnancy (usually affected with a condition) who brought the family to the attention of the recorder. An arrow at the lower left hand corner of a symbol indicates the proband in the pedigree. The consultand (please be careful your spellchecker doesn't change this to consultant!) is the person/persons who is/are seeking genetic counseling. He/she may or may not be the same as the proband. The letter C at the lower corner of the symbol denotes the consultand(s); there may be more than one.

- **Condensing the pedigree**

Condensing a pedigree allows removal of individuals and information extraneous to the clinical story. Some individuals may be chosen to stay in the pedigree due to their psycho/social relationship with the consultand/proband, rather than for their strictly clinical or medical findings.
The usual persons deleted include the non-contributory spouses of individuals and their ancestors. If this occurs, then the line of descent passes from the sibship of interest to the centers of the symbols for the parent who remains in the pedigree. This is most useful when documenting the nature of consanguinity since the inclusion of the extra persons may mask true nature of multiple descent lines.

Using a number inside a symbol can represent more than one non-contributory individual. The number may be used inside a circle and square separately, or combined in a circle drawn within a square, to designate the number of sibs of the respective sex, or the combined number of sibs of both sexes respectively. A diamond with a number inside represents the number of sibs of unidentified sex.

Conventionally all references to names, dates of birth, and other identifying information is eliminated from the pedigree. The relevant information about the proband and consultands and other important persons to the case should be incorporated in the narrative or in the key. Description of the individuals in the narrative may include their pedigree reference number for easy identification in the family tree.

- **Key or legend**

The legend or key is one of the most important parts of the pedigree. It need not specify the meaning of the conventional symbols (as Cyrillic automatically does), but the markings (inside and outside the symbol) used to designate clinical findings (including mutation types identified) and any unconventional symbols should be specified. Any abbreviation used should also be explained in the key. The key should be placed in a good location, such as the upper right corner, where it does not interfere with the drawing or the numbering.

- **Numbering**

Assignment of symbol identification numbers should be one of the last steps to the pedigree drawing. Generations are numbered by Roman numerals (i.e. I, II , III, IV, etc) in descending order (oldest generation assigned number I) along a vertical line to the left of the pedigree. Individuals within a generation are numbered from left to right with Arabic numbers (1, 2, 3, etc) at the lower right hand corner of the individual symbols. Each pregnancy gets a number, even if not continued to term. In cases where a symbol represents more than one individual, the appropriate range of numbers (i.e. 5-8) should be used at the lower right hand corner of the symbol. Symbols placed out of line from their siblings are numbered in sequence with the generation in which they are placed, not in sequence with their siblings. Note that some programs like Cyrillic might automatically number symbols as they are added to the pedigree and also allow more than one person to have the same number. These formatting problems are the most common revisions required from Board applicants and can be avoided by checking the numbering formatting during the review process PRIOR to submission.

CASE (number)

Title of case

GENETIC REASON FOR REFERRAL

COUNSELLING REASON FOR REFERRAL

As perceived by the client:

As perceived by the counsellor:

PRE COUNSELLING CONTACT

BACKGROUND

Demographics, social issues, family dynamics

COUNSELLING SESSION ONE:

Present:

Outline of session:

Issues raised by consultands:

Issues raised by the counsellor:

As well as a description of the case, the Board is also looking to see what the role of the counsellor has been in the case and the skills and interventions the genetic counsellor utilised in the case. The Board is also looking to see what the significant counselling issues were raised in the case, that they have been identified by the AGC and discussed in the counselling discussion (i.e. that the counselling discussion is relevant to the issues raised by the case).

COUNSELLING SESSION ONE (cont'd):

Outcome of counselling:

SUBSEQUENT CONTACT:

Outcome of contact:

COUNSELLING SESSION (Two/ Three – optional)

It is expected that candidates who are submitting latter cases (i.e. from 10 onwards) that some cases contain more then one genetic counselling session. This enables the candidate to demonstrate that they are managing more complex cases and their skill development continues to evolve i.e. breadth of skills the counsellor is able to utilise in their practice.

COUNSELLING SUPERVISION:

Nature and content of supervision received specific to the case.
What has the AGC learned from supervision?

GENETIC SUPERVISION:

Nature and content of supervision received specific to the case.
What has the AGC learned from supervision?

SUMMARY OF ISSUES:

Summarise the issues the case raised and choose one or two to expand on in the discussion

DISCUSSION OF COUNSELLING ISSUES:

In the counselling issues discussion you should be able to highlight the important counselling issues and discuss in detail the counselling interventions you used and demonstrate that those interventions are based on sound understanding of counselling theory.

Choose one or two important issues, which the case raised to explore in the discussion with support from the literature. Relate the theory to the case throughout the discussion.

Minimum word count: 400 - 600

As candidate moves through Part 2, the Board is looking at their professional development. It is expected that this be demonstrated and reflected in the increasing complexity of cases presented, the breadth of skills the counsellor is able to utilise in their practice, the depth of case analysis, and a greater level of self-awareness.

GENETICS:

Minimum word count: 400

Summary of condition
eg CF is an A/R disorder due to mutations in the CFTR gene and is characterised by effects ...

Demographics
prevalence, ethnic influences, age of onset and natural history

Clinical features

Genetics
- inheritance pattern and recurrence risks
- gene/biochemistry/pathology as applicable
- genotype phenotype correlations

Management

Prenatal diagnosis

REFERENCES:

See page 35 of the training guidelines for information re referencing.
References should be recent, accurate and complete.
Patient brochures/literature and wedsites are NOT a suitable reference source.

PEDIGREE

See page 37 of the training guidelines for information re referencing.

C. SUPERVISION

Supervision is an accepted requirement in many professions. Supervision may mean administrative accountability or discussion of work related issues. In this context, supervision encompasses administrative, educational and supportive functions. It is a mutually agreed upon relationship with a contract between both parties.

Superision is <u>mandatory</u> for Part 2 training in Genetic Counselling. The concept of genetic counselling, comprising the two areas of genetics and counselling, requires the involvement of a supervisor in each area. Thus the candidate is required to arrange supervision for both counselling and genetics. The supervisors should have a greater level of experience in their professional area than the supervisee and have recognised experience in supervision. It is recognised that such requirements may impose difficulties for candidates who are isolated geographically, but candidates are encouraged to seek supervisors from the community as well as their employing agency.

Supervision implies that the candidate and the supervisor set aside a regular time. It is recognised that this will involve **2 hours per week equivalent** in total: 1 hour per week equivalent separately for genetics and counselling. However, group supervision is an alternative and can be arranged in larger cities through voluntary counselling agencies, clinical psychologists and social workers in private practice who are experienced in group supervision. Both outreach and main unit trainees have effectively employed group supervision models. The Board can provide guidance and suggestions as to the most effective implementation of such a proposal.

Candidates undertaking Part 1 training who also have substantial autonomy and are counselling patients and families independently, e.g. in an outreach setting, should preferably also have regular and formal supervision arrangements. Such supervision not only supplements professional development but also provides a measure of legal protection for the candidate.

It is in the interest of the candidate that the two supervisors, i.e. for genetics and counselling, discuss the candidates progress in each area every 6 months to enable positive feedback. Any concerns regarding the candidate's progress in any area should however be discussed with the candidate.

Supervision is best facilitated with the use of a contract. This is standard practice with all supervision arrangements in other disciplines. A contract should be drawn up by the candidate and the details negotiated with the supervisor. Contracts can be reviewed every six (6) months or at intervals nominated by the participants.

While confidentiality in regard to personal issues is an integral part of the supervision sessions, the contract should note that discussions will be held between the two supervisors regarding the candidate's progress and this principle should be observed.

Below is a sample contract template that candidates could consider using with their supervisors. Contracts should apply to both genetics and counselling supervision.

CONTRACT BETWEEN SUPERVISEE AND SUPERVISOR

How often will we meet?
What venue will we use?
How will each session be structured?
How will we determine the content of each session?
What are the responsibilities of the supervisor?
What are the responsibilities of the supervisee?
A statement about the need for confidentiality.

A statement about the manner in which conflict between the supervisor and supervisee will be addressed.
The goals of supervision based on those outlined below in the guidelines plus any additional goals. These goals can be most usefully divided into the following categories:

- Administrative goals
- Educational goals
- Support goals

Review period of contract.

GENETICS/GENETIC COUNSELLING SUPERVISION

For supervision in the area of genetics, the supervisor should be an HGSA Certified Clinical Geneticist with whom the supervisees can discuss genetic, genetic counselling and medical issues that arise.

Upon the completion of Parts 1 and 2 of training in genetic counselling, the candidate should have developed the following skills and attitudes. The list can be used by both the supervisor and the supervisee to structure the supervision time and as an aid in assessing the supervisee's progress.

Skills

To synthesise information and to develop the ability to communicate it clearly, non-directively, and without personal bias to people from greatly differing education, socioeconomic and ethnic backgrounds.

1. To recognise when referrals are appropriate both in relation to referral source and the nature of the problem and to ensure that the counsellee understands the reason(s) for the referral.

2. To become sufficiently familiar with the many components of a medical record in order to be able to find specific data and to recognise what is most likely to be pertinent to the genetic issues(s).

3. To construct a pedigree appropriate to the genetic problem at hand, to calculate recurrence risks, to recognise significant gaps in information and/or misinformation.

4. To carry out genetic counselling under the supervision of the clinical geneticist and to draft summary consultation letters to counsellees and referring physicians.
   It is anticipated that at the completion of training, candidates will be able to provide effective and competent genetic counselling alone, across a wide range of situations. Such situations might include a discussion of prenatal diagnosis testing, genes, chromosomes and translocations, basic Mendelian inheritance and gonadal mosaicism, multifactorial and mitochondrial inheritance, uniparental disomy, exposure of the fetus to some basic teratogens, DNA testing and the completion of standard consent forms for DNA testing. This list is a sample of the kinds of counselling situations which genetic counsellors might be required to handle independently. However, it is not an exhaustive list and as counsellors become more proficient, the tasks required of them will become more complex.

   It is important that candidates not only have a firm understanding of these more common genetic concepts but can also transmit the information in a manner appropriate to each client so it can be understood by the client at his or her level of comprehension.

5. To become familiar with and to develop a working facility with a wide variety of sources of genetic data; e.g. birth defects atlases and other texts, current literature searches (Medline, Current Contents, McKusick Catalogue), audiovisual materials, computer-assisted diagnosis.
6. To determine whether the client/family might benefit from contact with community agencies e.g. social services, specific genetic support groups, and to maintain an up-to-date file of such agencies. An ideal genetics service includes social workers trained in genetics - the counsellor and social worker should work out a definition of responsibilities and sharing of activities in a team approach.

7. To anticipate potential counselling problems during the telephone inquiry or the initial meeting that might interfere with the exchange of information and to inform the clinical geneticist of them (e.g. language problems, marital instability, doubtful paternity).

8. To anticipate situations where follow-up on the genetic counselling session is required/advisable e.g. home visits/telephone call, in patient/short-stay visit in relation to procedures (CVS, amnio, TOP, etc), reminder of appointments, referral to other health care professionals such as social workers, psychologists, psychiatric clinics, family planning clinics etc.

9. To develop knowledge of medical terminology format and content of medical and genetic histories.

10. To develop awareness and understanding of the moral and ethical issues in particular cases.

11. To work in a multidisciplinary team, and within the organisation.

12. To be aware of current and developing technologies in all areas of genetics.

Attitudes

To become an empathetic, sensitive, non-judgemental and non-directive genetic counsellor who recognises his/her personal limitations and who seeks additional help and supervision where appropriate.

1. To develop the ability to present all of the options fairly, accurately and non-directively. The genetic counsellor must not answer the questions "What would you do if you were in my/our position?". If advice is sought by the counsellee, referral to the clinical geneticist is appropriate.

2. To become a life-long, self-directed learner who is aware of available educational resources, how to access them effectively, and how to critically appraise their usefulness.

3. To be a willing and enthusiastic participant in education activities for other health care professionals, students at all levels, and the public.
4. To understand the importance of research and to participate where appropriate.

Guidelines for the Supervisor

The supervision sessions may involve discussion of one case or discussion of several cases. Monthly signing of the log book is mandatory to confirm that the candidate has indeed actively participated in the genetic counselling in each case and this provides an opportunity to review the log book content to ensure that the candidate is gaining the necessary breadth of experience. The supervision sessions are also an opportunity for discussion regarding the case load of the candidate and to review written work e.g. letters and case studies.

A regular time should be set aside for supervision with the candidate, some of which should be face to face while some may be in group supervision.

The skills and attitudes listed can be used as a guide for monitoring and assessing the supervisee's progress.
An assessment report must be submitted to the Board of Censors annually indicating that adequate progress in the areas outlined for supervision have been made but may also include areas where professional development should be extended. Please address the skills and attitudes detailed above when assessing the candidate’s progress and evaluating skills still to be developed. This assessment should also include discussion about the candidates case reports. The candidate should supply the supervisor with the correct form for submission of the report. The supervisor should forward six (6) copies of every report to the Board.

The supervisor is also required to indicate the nature of the supervision (interview/group - number in group should be detailed) and the time spent with the candidate. Discussions with the counselling supervisor should be held every 6 months to ensure that the candidate is progressing satisfactorily in both areas under supervision. However the principles of confidentiality should be observed during this discussion.

Guidelines for the Supervisee

Supervision of at least one hour per week equivalent in genetics/genetic counselling is mandatory for Part 2 training and certification and it is the responsibility of the candidate to arrange suitable supervision. If the candidate is finding the supervision unsatisfactory, the candidate should discuss the situation with the supervisor and attempt to find a more suitable arrangement.

The supervision sessions are also an opportunity for discussion regarding the case load of the candidate and to review written work e.g. letters and case studies.

Twenty case studies are to be written for submission to the Board as part of the documentation required for Part 2 training. Each case is to be written by the candidate but must include a paragraph on the content of supervision received regarding this case.

Both the supervisor and the supervisee should have copies of these guidelines and desired outcomes.

A report is required annually on the supervisee's progress. A form is included with these guidelines for use by the supervisor and should be provided by the supervisee. Supervisor’s reports may be discussed with the candidate prior to forwarding with the submission to the Board.

COUNSELLING SUPERVISION

For supervision in the area of counselling, the supervisor should be a qualified counsellor, with a counselling expertise greater than the supervisee. The supervisor should have knowledge of, and be aware of, the agency issues and caseload issues of the supervisee. Suggested supervisors are accredited social workers in hospital or community settings with not less than three years experience, accredited clinical psychologists in hospital or community settings or an HGSA Certified Genetic Counsellor, two years post certification, who has continued having supervision.

Upon the completion of Parts 1 and 2 of training in genetic counselling, the candidate should have developed the following skills and attitudes. The list can be used by both the supervisor and the supervisee to structure the supervision time and as an aid in assessing the supervisee's progress.

Skills

To synthesise information and to develop the ability to communicate it clearly, non-directively and without personal bias to people from greatly differing education, socio-economic and ethnic backgrounds.

1. To develop the ability to cope emotionally with responses of clients, especially unexpected ones (e.g. anger towards health professionals and/or hospitals, anger directed at the counsellor, guilt at having been the one to pass on a harmful trait or to have exposed a conceptus to a teratogen).

2. To learn the techniques of conveying bad news.

3. To recognise people's defence mechanisms and decide when to leave them intact.

4. To develop self-awareness, e.g. about attitudes towards race, moral issues, social class, religion.

5. To individualise each person. Factors such as social class, education or religion may not determine the level of understanding, reactions or decisions made by people (e.g. to risk factors).

6. To be aware of the wide range of normal reactions to factors such as grief and an ability to tolerate reactions different from those of the counsellor.

7. To be aware of emotional reactions often encountered in genetic counselling such as chronic sorrow, stigma, grief, guilt, denial, mechanisms of coping and how they are expressed.

8. To understand how factors in the individual’s past may affect his/her present functioning e.g. past encounters of disability.

9. To be sensitive to the current situation of the counsellee and how that may decrease ability to participate effectively in the interview, e.g. grief, financial stress.

10. To learn the normal developmental stages of human behaviour, maturation and intelligence in order to facilitate counselling individuals of varying ages.

11. To have a basic understanding of personality dysfunction.

12. To be aware of cultural and social attitudes to issues such as reproduction, termination, parental roles and sex roles.

13. To recognise the levels of communication within an interview and to learn to use different communication techniques within an interview e.g. establishing empathy, use of open-ended questions, interpretation, allowing ventilation, non-judgemental attitudes, generalisation, reflection, confrontation, acknowledging feelings etc.

14. To recognise the need for tolerance of reiteration of information because of counsellee's anxiety or unfamiliarity with the concepts discussed.

15. To have an awareness of the decision-making process and how to facilitate this process.

Attitudes

To become a sympathetic, sensitive, non-judgemental and non-directive genetic counsellor who recognises his/her own personal limitations and who seeks additional help and supervision whenever appropriate.

1. To develop skills to recognise and to appreciate the counsellee's religion, moral and ethical beliefs and biases in order to avoid imposing the counsellor's beliefs and biases on the client. The counsellor must not preach to the counsellee.

2. To find methods of self and/or peer evaluation of comprehension of new knowledge and use of new skills.

Guidelines for the Supervisor

The supervision sessions may involve discussion of one case or discussion of several cases. Counselling issues and outcomes in these cases, including appropriate referrals, can be discussed. Different techniques of counselling should be discussed. The supervisor needs to facilitate discussion about issues of self-awareness in the counselling role in a supportive, non-judgemental way.

A contract should be drawn up and a regular time should be set aside for supervision with the supervises, some of which should be face to face while some may be in group supervision or by the telephone.

The skills and attitudes listed can be used as a guide for monitoring and assessing the supervisee's progress. An assessment report must be submitted to the Board of Censors annually, indicating that adequate progress in the areas outlined for supervision have been made but may also include areas where professional development should be extended. Please address the skills and attitudes detailed above when assessing the candidate's progress and evaluating skills still to be developed. This assessment should also include discussion about the candidate's case reports. The candidate should supply the supervisor with the correct form for submission of the report. The supervisor should forward six (6) copies of every report to the Board.

The supervisor is also required to indicate the nature of the supervision (interview/group - number in group should be detailed) and the time spent with the candidate.

Discussions with the genetic/genetic counselling supervisor should be held every six months to ensure that the candidate is progressing satisfactorily in both areas under supervision. However the principles of confidentiality should be observed during this discussion.

Guidelines for the Supervisee

Supervision of at least 1 hour per week equivalent in counselling is mandatory for Part 2 training and certification and it is the responsibility of the candidate to arrange suitable supervision. If the candidate is finding the supervision unsatisfactory, the candidate should discuss the situation with the supervisor and attempt to find a more suitable arrangement.

Supervision does not mean personal psychotherapy. Whilst it is often appropriate to discuss and raise personal issues that affect case management, treatment of personal issues usually remains separate from supervision sessions. The supervisor and genetic counsellor may agree that referral is indicated for personal issues, but this should be done separately.

Twenty case studies are to be written for submission to the Board as part of the documentation required for Part 2 training. Each case is to be written by the candidate but must include a paragraph outlining the content of supervision received regarding this case.

Both the supervisor and the supervisee should have copies of these guidelines and desired outcomes.

A report is required annually on the supervisee's progress. A proforma is included with these guidelines (page 71) for use by the supervisors and should be provided by the supervisee. Supervisor's reports may be discussed with the candidate prior to forwarding with the submission to the Board.

D. CONTINUING EDUCATION

Any candidate who is applying for Part 2 will have met the requirements for Part 1 and have undertaken formal qualifications in the areas of genetics and counselling. However, granting of Part 2 requires supplementation of this formal course work by in-service training and experience in a Clinical Genetics Unit. Such in-service training will comprise seminars, conferences, workshops, in-service courses and experience in all aspects of the genetic counsellor's role. The annual submission to the Board should list the areas and formats of such training.

While the observation of a genetic counselling session cannot be included as part of the log book documentation it is valid to include this as part of your continuing education and training in this section of your submission.

In the area of genetics, professional development is essential to ensure the candidate's knowledge is current. Attendance at journal clubs and/or a list of the journals and texts that are consulted should be provided.

In the area of counselling, further development of those skills listed under Part 1 should be attained by application to genetic counselling. Professional development and regular supervision covering the areas as outlined in the Supervision section should be undertaken. A list of the texts and articles consulted should be provided.

APPLICATION FORMS FOR HGSA CERTIFICATION IN GENETIC COUNSELLING (PART 2)

The following forms are to be used for applications to the HGSA Board of Censors for Certification in Genetic Counselling. Separate forms are to be used for Part 1 and 2. In most cases, a candidate will apply for Part 1 prior to applying for Part 2.

The closing dates for submission each year are January 31 and July 31. Whenever a submission is made to the Board a total of four (4) copies of the submission should be sent to the Secretary of the Board of Censors for Genetic Counselling. Please note that applications will not be accepted if they are not received by the due date and do not include four (4) copies of every page including any covering letter.

This Part 2 application form should accompany all submissions to the Board regarding prospective approval of a training program. Where training is approved, the Board will advise the candidate that successful completion of the proposed training supported by the required documentation and supervisors' assessments will be recognised as credit towards certification.

The Board will also provide the candidate with retrospective recognition of training completed when this occurs.

Annual submissions for Part 2 should include log book evidence of 50 cases per year (or pro-rata) covering the recommended areas, supervisors' reports (under separate cover) estimates of time spent undertaking the various duties as a genetic counsellor and details of continuing education.

One or more case studies may be submitted at each date to enable feedback. The Board will not accept more than five (5) case studies per six month period i.e. a maximum of ten (10) per year.

CERTIFICATION

The Board will recommend a candidate for HGSA Certification in Genetic Counselling when all the required training for Part 1 and 2 have been completed and supporting documentation has been provided.

The current Board Chair is Annette Hattam. Please send **four (4) copies** of each submission to:

HGSA Board of Censors for Genetic Counselling
C/- HGSA Secretariat
PO Box 362
Alexandra VIC 3714
Tel: 03 5772 2779
Email: hgsa@racp.edu.au

The submissions must be accompanied by the appropriate fee as detailed on page 80 of these guidelines.

APPLICATION FOR HGSA CERTIFICATION IN GENETIC COUNSELLING

PART 2

NAME: ____

ADDRESS:____

____

TELEPHONE: ________________________ FAX: ______________________

DATE OF BIRTH: ____

CURRENT EMPLOYER:

____

ADDRESS:____

____

TELEPHONE: ______________________ FAX: __________________________

FULL TIME/PART TIME EMPLOYMENT (HOURS PER WEEK IF PART TIME)

____

GENETICS/GENETIC COUNSELLING SUPERVISOR:

NAME: ____

ADDRESS: ____

____

TELEPHONE: __________________________ FAX: __________________

COUNSELLING SUPERVISOR:

NAME: ____

ADDRESS: ____

____

TELEPHONE: __________________________ FAX: __________________

INITIAL SUBMISSION DATE: ______________________________________

DATE OF THIS SUBMISSION: _____________________________________

HAVE YOU INCLUDED FOUR (4) COPIES OF <u>EVERY</u> SHEET YOU ARE SENDING WITH THIS APPLICATION (INCLUDING THESE PAGES)?

PROFORMA FOR COUNSELLING SUPERVISOR'S REPORT

This form is to be used by your counselling supervisor to provide us with an accurate picture of your progress to date. The supervisor's report is a vital component of training and the Board of Censors for Genetic Counselling requires that reports submitted be comprehensive and focused on the goals for supervision as laid out in the Guidelines for training in Genetic Counselling. This template is based on those objectives and by using it for report writing, your supervisor will be able to identify areas requiring more attention in supervision sessions. It will be helpful for you to discuss your supervisor's comments with him or her prior to submitting this report. Failure to provide this assessment of progress may jeopardise the candidate's certification.

An example of how this proforma might be completed follows.

> Under the heading below "Has developed a level of self-awareness etc" the supervisor might write:
> **"The candidate's life experiences have increased her own self awareness. She understands that clients don't always make the same decisions she might. She also has a good understanding of the complex ethical dilemmas which client's often face."**

This comment provides evidence that the candidate has made substantial progress in that particular area. An example of how the candidate implements each point in his or her counselling sessions with clients will help the Board gain an understanding of his or her performance.

CANDIDATE'S NAME: ____

DATE OF COMPLETION OF REPORT: _____________________________

SUPERVISOR'S NAME: ____

SUPERVISOR'S QUALIFICATIONS AND EXPERIENCE (IN BRIEF):

___

___

___

___

SKILL	SUPERVISOR’S COMMENTS AND AN EXAMPLE OF SKILL APPLICATION WHERE POSSIBLE
Understands and can apply the techniques of giving bad news.	
Understands and can apply the skills necessary for effective communication: empathy, open-ended questions, ventilation, reflection, non-judgmental attitude, acknowledges feelings appropriately etc	
Understands the decision making process and can facilitate this effectively.	
Can cope with and effectively manage a range of unexpected client responses eg anger, guilt, grief.	
Has knowledge of normal human developmental stages and associated behaviours; can use this knowledge in the counselling setting.	
Recognises and respects the role of defense mechanisms.	
Can individualise each client; recognises that social class, gender, education, religion etc do not necessarily determine client reactions or decisions.	
Understands the grieving process and is comfortable providing unconditional support.	
Is aware of and can effectively address emotional reactions often encountered in genetic counselling eg chronic sorrow, stigma, grief, guilt, anxiety etc.	

Understands how a client's past experience may play a role in dealing with the current crisis.	
Has some understanding of personality dysfunction.	
Is aware of cultural and social attitudes to issues such as reproduction, termination of pregnancy, parental and gender role differentiation.	
Has developed a level of self awareness about attitudes to race, religion, moral and ethical beliefs etc and can put these to one side when counselling.	
Can utilise the supervision process effectively, is well prepared and committed to developing counselling skills.	

ANY OTHER COMMENTS ABOUT THE CANDIDATE'S PROGRESS:

PROFORMA FOR GENETIC SUPERVISOR'S REPORT

This form is to be used by your genetics supervisor to provide us with an accurate picture of your progress to date. The supervisor's report is a vital component of training and the Board of Censors for Genetic Counselling requires that reports submitted be comprehensive and focused on the goals for supervision as laid out in the Guidelines for training in Genetic Counselling. This template is based on those objectives and by using it for report writing, your supervisor will be able to identify areas requiring more attention in supervision sessions. It will be helpful for you to discuss your supervisor's comments with him or her prior to submitting this report. Failure to provide this assessment of progress may jeopardise the candidate's certification.

An example of how this proforma might be completed follows.

Under the heading below "Can calculate recurrence risks", the supervisor might write: **"The candidate regularly sees couples for consanguinity counselling and I am confident is able to calculate risks appropriately. We discuss these prior to and following the counselling session and if she has any concerns these are addressed before the patient is seen."**

This comment provides evidence that the candidate has made satisfactory progress in that particular area. An example of how the candidate implements or demonstrates each skill will help the Board gain an understanding of his or her performance.

CANDIDATE'S NAME: ____

DATE OF COMPLETION OF REPORT: _____________________________

SUPERVISOR'S NAME: ____

SKILL	SUPERVISOR'S COMMENTS AND EXAMPLE OF SKILL APPLICATION WHERE POSSIBLE
Has an understanding of the referral process and what constitutes an appropriate referral to the service.	
Can utilise a medical record effectively; has a satisfactory grasp of relevant medical terminology.	
Can construct a satisfactory and appropriate genetic pedigree.	
Can calculate recurrence risks.	
Can carry out genetic counselling under the supervision of the clinical geneticist. Please specify which situations you believe the candidate has achieved a satisfactory level of competence eg. prenatal diagnosis; inheritance patterns, (Mendelian, gonadal mosaicism, multifactorial, mitochondrial, uniparental disomy etc); genes and chromosomes; translocations; exposure to some basic teratogens; DNA testing; cancer genetics; HD etc.	
Can transmit information in an appropriate manner which can be understood by each client at his or her level of comprehension.	
Is familiar with and uses a wide range of genetic data sources eg. Birth defects texts; current journals; on-line literature searches eg Medline, McKusick etc; audiovisual materials as appropriate.	
Can undertake a comprehensive intake including identifying potential problems which might impact on the counselling session eg language or marital problems; doubtful paternity etc.	

Can identify situations in which follow-up is required; can provide appropriate follow-up eg revision of information received, referral to other professionals, talking to other family members etc.	
Has an awareness and understanding of the moral and ethical issues in particular cases.	
Can work as an effective team member.	
Is aware of current and developing technologies; takes an active interest in genetic advances.	
Participates in educational activities to enhance the genetic knowledge of other professionals.	
Has an awareness of HGSA Best Practice Guidelines for Genetic Counselling.	

ANY OTHER COMMENTS ABOUT THE CANDIDATE'S PROGRESS:

SECTION : COSTS OF APPLICATIONS FOR CERTIFICATION

The HGSA requires that its Boards of Censors be self-supporting. Thus fees are charged for submissions to the Board of Censors in Genetic Counselling to fund the meetings and administrative costs incurred.

A total of $440.00 is charged for HGSA Certification in Genetic Counselling, chargeable in the following manner:

PART 1

$110.00 Submission to the Board for approval of proposed courses or retrospective approval of previous courses undertaken as well as recognition of successful completion of approved courses. This fee covers all submissions until Part 1 is awarded for both genetics and counselling. No certificate is issued on completion of Part 1 training.

PART 2

$330.00 Submission to the Board for approval of proposed training and retrospective recognition of training completed. This fee covers all submissions to the Board regarding Part 2 training until a recommendation is made to the HGSA Council for the award of Part 2.

Successful completion of Part 1 and 2 will result in the award of Certification in Genetic Counselling by the HGSA.

No further fee is required following receipt by the candidate of the Board's recommendation for HGSA Certification to the Council. A certificate will be issued as evidence of Certification.

Cheques made payable to the HGSA must accompany the initial applications for Part 1 and 2.

E. MAINTENANCE OF PROFESSIONAL STANDARDS PROGRAM

INTRODUCTION

This document outlines the procedures to be undertaken by Certified Genetic Counsellors through a program of Maintenance of Professional Standards (MOPS). The program will be administered by the Human Genetics Society of Australasia through its Board of Censors for Genetic Counselling.

Similar programs are currently undertaken by a number of professions in order to maintain individual professional registration by a relevant body, ensure the highest possible professional standards of practice and to maintain the right to practise in that particular discipline. Such Registration Boards include the Boards of Optometry, Chiropracty, Nursing, Medical, Psychology, Physiotherapy etc.

There is no registration of Genetic Counsellors at present and improbable that this will eventuate in the future. However, the Board of Censors has an expectation that counsellors will be committed to the goal of Continuing Professional Education through the enhancement and maintenance of existing skills and the development of new learning directions to meet individual professional needs. It is anticipated therefore, that all certified genetic counsellors will participate in the program.

PROGRAM STRUCTURE

The structure of the program aims to enhance learning in the areas of
1. Genetics, Counselling and Genetic Counselling theory and
2. The Practice of Genetic Counselling.

Flexibility in learning options has been employed as the Board of Censors is mindful of the difficulties that can be experienced by outreach counsellors in terms of accessibility to in-service activities. The Board is also mindful of the need to minimise the costs incurred for candidates enrolled in the program. The format outlined is intended to be a guide for participants and **the list of activities is by no means exhaustive.** Counsellors are encouraged to seek out relevant learning experiences for themselves in order to meet their own training requirements.

The program is designed to be completed over a three year period, during which time 70 credit points are to be accumulated. Forty of these should be from the area Genetics, Counselling and Genetic Counselling theory and 30 from The Practice of Genetic Counselling.

The point allocation will apply to both full time and part time genetic counsellors. The rationale for this decision is based on the need to maintain a professional standard irrespective of the number of hours worked. Similarly, those undertaking maternity or unpaid leave will be subject to the same requirements. As the progam has a three year cycle, it is anticipated that this length of time will provide sufficient flexibility for successful completion.

A table outlining credit point allocation follows.

IMPLEMENTATION OF THE PROGRAM

Each genetic counsellor will register with the Board of Censors her/his intention to undertake the program. Submissions to the Board from that time will be every 18 months ie. two submissions per cycle on either January 31st or July 31st of any year. The points do not have to be evenly divided between these submissions, but total 70 at the completion of the cycle. There will be a cost attached of $50 every three years to cover the Board's processing expenses.

The pro forma at the back of this document can be photocopied for use. Please include all three pages with each submission.

If a candidate wishes to undertake a program of learning which has not been outlined by the Board, this proposal should be submitted prior to commencement where possible, to allow the Board to consider the benefits of the project and the number of points it is to be awarded. Where a project cannot be assessed by the Board prior to commencement, it may be submitted retrospectively.

The Board will audit submissions randomly at each sitting. Candidates will not have to submit details of every activity undertaken during the program ie. each journal club or supervision session does not need to be recorded, just the total of such sessions listed. However, it will be important for your own records to keep these details in event of an audit at which time the Board will want to see them.

SUPERVISION

Supervision is an integral component for anyone working in an area requiring complex social interaction, assessment of another's psychological state and judgements about appropriate intervention. Supervision serves to provide the opportunity to assess situations objectively and to seek a second opinion from a mentor. In no way is it designed to be judgemental or critical of the supervisee, but supportive and instructive. It is therefore considered important that genetic counsellors, when certified, endeavour to maintain a relationship with a supervisor on a regular basis, convenient to both parties and meeting the needs of the supervisee.

LEARNING ACTIVITY OPTIONS	MAXIMUM CREDIT POINTS ACCUMULATED OVER 3 YEARS	METHOD OF ACCUMULATION OF CREDIT POINTS
GENETIC, COUNSELLING AND GENETIC COUNSELLING THEORY		
Formal course work in genetics at a tertiary institution	20 points	10 points for each unit completed
Formal course work in counselling theory and practice at a recognised tertiary or training institution	20 points	10 points for each unit completed
Other relevant course work at a tertiary institution	20 points	10 points for each unit completed
Attending individual relevant lectures	20 points	1 point for each lecture
Attending relevant conferences or workshops but not making a presentation	10 points	1 point for each hour attended
Giving an oral presentation or submitting a poster to relevant conferences or workshops	9 points	3 points for each presentation or poster
Self directed reading in genetics	6 points	3 points for each bibliography
Self directed reading in counselling	6 points	3 points for each bibliography
Relevant journal club (must be included on roster)	5 points	1 point for each meeting
Relevant inservice education	5 points	1 point for each meeting
Teaching in a relevant area	10 points	2 points for each lecture
Conducting research relevant to genetic counselling	20 points	15 points for being the principal researcher in a published report; 10 points for other published reports; 5 points for unpublished report
THE PRACTICE OF GENETIC COUNSELLING		
Annual staff appraisals	3 points	1 point for each appraisal
Genetics supervision	20 points	1 point for each hour
Counselling supervision -	20 points	1 point for each hour
Supervision of genetic counselling students on placement	20 points	3 points for each day of supervision
Active membership of a relevant committee	6 points	1 point for each year of membership per committee; 2 points if office bearer
Involvement with support groups	6 points	1 point for each involvement or meeting attended
Supervision of genetic counsellors	10 points	1 point for each hour of supervision facilitated
Quality assurance -conduct of a QA project -peer review -preparation of log book demonstrating breadth of experience or furthering experience -preparation of 5 long cases including analysis of genetics and counselling issues	 10 points 6 points 15 points 10 points	 5 points for each project 1 point for each meeting 5 points for each year the logbook is completed 2 points for each long case

EXPLANATION OF THE CREDIT CATEGORIES

Genetics and Counselling supervision

Supervision is an integral part of professional practice for those in occupations such as Genetic Counselling, Social Work etc. It is considered best practice if this is continued on a regular basis after certification or registration procedures are completed.
For this reason, supervision has been allocated 20 out of a necessary 30 points to encourage candidates to continue this process post certification as it is acknowledged as an excellent learning tool.

Formal counselling work in genetics or counselling at a tertiary institution or recognised training institution

Examples of such work could be extending genetics and/or counselling knowledge through a Masters or PhD study; Masters in Family Therapy through Relationships Australia etc. Such courses have an assessment component that would need to be completed.

Other relevant course work at a tertiary institution

Such courses could involve a one-unit special interest course eg. in molecular genetics via distance education.

Individual relevant lecture

These could be lectures attended for example during a Fellow's training program; visiting expert guest speakers; Grand Rounds etc.

Relevant conferences

HGSA meetings, annual Hereditary Cancer meetings, COSA meetings etc.

Relevant workshops

Australasian Society of Genetic Counsellors workshop; specific skills training workshops eg. grief counselling workshops etc.

Self directed reading in genetics or counselling

A bibliography of relevant journal and/or books would need to be submitted prior to commencement, outlining the aims of the reading project and intention behind the selection eg. readings aimed at increasing knowledge and understanding of aspects of cancer genetics; focussing on implications of prenatal testing for particular cultural groups. Confirmation that the choice of readings has been discussed with your supervisor will need to be included in your submission to the Board.

Relevant journal club attendance and presentation

Relevant, recognised journal clubs will be available in some of the bigger centres. Genetic counsellors should endeavour to be included on the presentation roster and dates attended recorded.

Relevant in-service education

Programs run by the candidate's employer or unit.

Teaching in a relevant area

Includes lectures given to genetic counselling students, nurses, hospital staff, other professionals etc.

Membership of a relevant committee

Such committees could be support group organisations, HGSA working parties, committees or Executive etc.

Supervision of Genetic Counsellors

Points are allocated for formal supervision sessions

QA projects

On behalf of one's employer or unit, or if in outreach, a project which examined the efficacy of the clinic visit, patient satisfaction etc.

MAINTENANCE OF PROFESSIONAL STANDARDS

DATE OF THIS SUBMISSION ___________________________________

DATE OF COMMENCEMENT OF THREE YEAR CYCLE ______________

NAME ____

ADDRESS ____

EMPLOYER ____

DATE OF CERTIFICATION _____________________________________

POINTS ACCRUED TO DATE IN THREE YEAR CYCLE (IF APPLICABLE)

____

NAME OF GENETICS SUPERVISOR ______________________________

NAME OF COUNSELLING SUPERVISOR __________________________

I ____________________________declare that the following information is an accurate record of my professional and continuing education activities for the period stated.

G. Signature: ___________________________________

GENETICS, COUNSELLING AND GENETIC COUNSELLING THEORY

DATE	ACTIVITY	ACTIVITY DETAILS	POINTS
	Formal course work in genetics		
	Formal course work in counselling		
	Other formal course work		
	Lectures attended		
	Attendances at conferences or workshops		
	Presentations at conferences or workshops		
	Readings in genetics		
	Readings in counselling		
	Journal club attendances		
	Inservice education		
	Teaching		
	Research undertaken		

TOTAL POINTS ACCRUED ____________

THE PRACTICE OF GENETIC COUNSELLING

DATE	ACTIVITY	ACTIVITY DETAILS	POINTS
	Staff appraisals		
	Genetics supervision		
	Counselling supervision		
	Supervision of students		
	Committee membership		
	Support group involvement		
	Supervision of genetic counsellors		
	Quality assurance – QA project peer review Log book Long cases		

TOTAL POINTS ACCRUED _________

<u>THIS SUBMISSION</u>:

POINTS FOR GENETIC COUNSELLING THEORY: _________

POINTS FOR GENETIC COUNSELLING PRACTICE: _________

TOTAL: _________

POINTS ALREADY ACCRUED IN 3 YEAR CYCLE: _________

GRAND TOTAL: _________

RECOMMENDED READING LIST IN GENETIC COUNSELLING

The following list contains texts and papers recommended for study by candidates in the fields of genetics, counselling and genetic counselling.

The texts used in Part 1 should have been listed in the course detail forms and texts and articles consulted in Part 2 should be listed in the Continuing Education .

Genetics

BAKER DL, SCHUETTE JL, UHLMANN WR(1998). A Guide to Genetic Counselling. New York, Wiley Liss.

CONNOR M and FERGUSON-SMITH M (1997*) Essential Medical Genetics,* 5th ed. Oxford, Blackwell Science Ltd.

EELES R, PONDER BJ, EASTON DF, HORWICH A. (1996) *Genetic Predisposition to Cancer* 1st ed. Chapman and Hall UK.

EMERY EH and RIMOIN DL. (1996). Medical genetics principles and practice. Vol 10. (2nd edition). Churchill Livingstone Edinburgh.
(This is the standard larger text about the genetics of medical conditions).

GARDNER RJM and SUTHERLAND GR. (1996). *Chromosome abnormalities and genetic counselling.* Oxford Monographs, New York, Oxford University Press.
(Concise summary of chromosomal problems).

GORLIN RJ, PINDBORG OJ and COHEN MM (1990) *Syndromes of the Head and Neck*, 3rd ed. New York, McGraw-Hill.

GRAHAM J. *Smith's recognisable pattern of human deformations.* WB Saunders.
(This is the only book of deformations)

HARPER PS. (1998) Practical Genetic Counselling (4th edition). John Wright.
(This is the standard reference book for genetic counselling. The first ten chapters are an excellent summary of medical genetics in the pre DNA age. The rest of the book very briefly discusses the inheritance of various medical conditions) .

HEIM S and MITELMAN F (1995) *Cancer Cytogenetics: Chromosomal and Molecular Genetic Aberrations of Tumour Cells,* 2nd ed. John Wiley and Sons, New York.

JONES KL. (1998) *Smith's recognisable patterns of human malformations*. (4th edition). WB Saunders.
(This is the most widely used and fastest to consult syndrome book).

McKUSICK VA (1992) *Mendelian inheritance in man*. Vol 1 & 2 (10th Edition). Johns Hopkins University Press.
(This is the standard reference book about Mendelian and miotochondrial inheritance. Up to date versions can be obtained by computer using Angis (for information contact Tom Reisner on phone: (02) 9692 2948, fax: (02) 9909 1551, E-ail: reisner @angis.su.oz-au). This can be accessed by the University network (AARNET) or by modem and includes access to OMIM, the human gene database as well as a mouse gene database.

MEDICINES IN PREGNANCY. AUSTRALIAN DRUG EVALUATION COMMITTEE. (1992) *An Australian categorisation of risks of drug use in pregnancy.*
(2nd Edition).
(This gives a categorisation of the degree of teratogenic risk).

MENKO F. (1993) *Genetics of Colorectal Cancer for Clinical Practice.* Kluwer Academic

MOORE KL and PERSUAD TVN. (1993) *The developing human. Clinically orientated embryology.* (5th Edition). Saunders WB, Philadelphia.
(The title says it all!)

MULLER H, SCOTT RJ, WEBER W (1995) *Hereditary Cancer.* Karger.

SCARDEIN JL. (1985) *Chemically induced birth defects*. Marcel Dekker, New York.
(The most extensive book on teratology).

SCHINZEL A (1984) *Catalogue of Unbalanced Chromosome Aberrations in Man,* Berlin, Walter de Gruyter.

SCRIVER CR, BEAIDET AL, SLY WS and VALLE D (eds) (1995) *The Metabolic and Molecular Bases of Inherited Disease*. New York, McGraw-Hill Inc.

SHEPARD TH (1998) *Catalog of Teratogenic Agents* (9th ed)

STRACHAN T, READ PR. (1996) *Human Molecular Genetics.* BIOS, Oxford.

THOMPSON AND THOMPSON (THOMPSON MW, McINNES RR AND WILLARD HF) (1991) *Genetics in Medicine* (5th edition). WB Saunders.
(This book is the most up to date of the smaller text books on medical genetics. It contains a lot of information about molecular genetics not contained in the other short books. However with publication in 1991, the information needs to be brought up to date).

TRENT RJ. (1997). *Molecular Medicine* Churchill Livingstone, London.
(This is the ideal *supplement for Thompson and Thompson to bring the information on molecular genetics up to* date).

VOGEL F and MOTULUSKY AG. (1986) *Human Genetics, Problems and Approaches*. Springer Verlag, Berlin.
(This is the best larger text on human genetics available, but is seriously out of date).

WEAVER DD (1998) *Catalog of Prenatally Diagnosed Conditions* (3rd ed)

YOUNG ID. (1991*) Introduction to risk calculation in genetic counselling* .
Oxford University Press.
(Short and relatively straightforward).

Counselling

Some of the texts on the following list may have been updated. It is recommended to access the most recent text.

Basic Texts:

1. **BRAMMER L.** (1988) *The helping relationship*. Prentice Hall.

2. **BOLTON R.** (1987) *People skills.* Simon Schuster.

3. **EGAN G.** (1986) *The skilled hellper* (3rd edition). Brook Cole.

4. **EGAN G.** (1986) *Exercises in helping skills* (3rd edition). Brooks Cole.

5. **EGAN G.** (1994) *The Skilled Helper: A Problem-Management Approach to Helping* (5th edition) Brooks Cole.

6. **EGAN G.** (1977) *You and me* Brooks Cole.

7. **GELDARD D.** (1998) *Basic personal counselling: A Training Manual for Counsellors* (3rd edition) Prentice Hall, Sydney.

8. **HARGIE 0., SAUNDERS C., DICKSON D.** (1981) *Social skills in interpersonal communication*. Croom Helm, London.

9. **KADUSHIN A.** (1983) *The social work interview* (2nd edition). Columbia Univ. Press.

10. **KENNEDY E and CHARLES S.** (1990) *On becoming a Counsellor: A Basic Guide for non-professional Counsellors.* Collins Dove, Victoria.

11. **KOTZMAN A.** (1989) *Listen to me listen to you*. Penguin.

12. **MARTIN R.J.** (1983) *A skills and strategies handbook for working with people*. Prentice Hall.

13. **NELSON-JONES R.** (1988) *Practical counselling and helping skills* (2nd edition). Holt Rinehart and Winston.

Further Reading:

BERGIN A.E., GARFIELD S.L. (1971) *Handbook of Psychotherapy and behaviour change*. Wiley, New York.

BAIDER L, COOPER CL, DE-NOUR AK. (2000) *Cqancer and the Family* 2nd ed. Wiley and Sons, England.

BUCKMAN AND KASON. (1992) *How to Break Bad News*. Papermac, London.

CARKHUFF R.R. (1969*) Helping and human relations*. Vol. 1 and 2. Holt, Rinehart and Wilson, New York.

CARKHUFF R.R. (1971) *The development of human resources*. Holt, Rinehart and Wilson. New York.

CLARKE A, PARSONS E, EDITORS (1997). *Culture, Kinship and Genes*. London, MacMillan.
CORSINI R.J. (1979). *Current psychotherapies*. Peacock Publishers, Illinois Press.

CARKHUFF R.R. (1974) *The art of problem solving*. Human Resources Development Press, Amherst Mass.

CARKHUFF R.R.(1974) *How to help yourself.* Human Resources Development Press, Amherst Mass.

CARKHUFF R.R., BERENSON B. (1976) *Teaching as treatment*. Human Resources Development Press, Amherst Mass.

CARKHUFF R.R., BERENSON B. (1977) *Beyond Counselling and Treatment* (2nd edition). Holt, Rinehart and Winston, New York.

DETTMAN C, SAUNDERS D. (1987) *The Chance of a Lifetime: Infertility and IVF*. Penguin Books.

FRIEDMAN R, GRADSTEIN B. (1982) *Surviving Pregnancy Loss*. Little, Brown and Company.

GUNTHER B. (1968) *Sense relaxation: below vour mind*. MacMillan, New York.

IISE S. (1993) *Precious Lives, Painful Choices. A prenatal decision-making guide.* Lakeland Press.

JANKOVIC J, BEACH J, ASHIZAWA T. (1995) *Emotional and Functional Impact of DNA Testing on Patients with Symptoms of Huntington Disease*. J Med Gen. 32:516-518

KOTZMAN A. (1983) *Self assertion, Student Readings.*

KUBLER-ROSS E. (1969) *On Death and Dying*. MacMillan Publishing Company.

MARTEAU T and RICHARDS M (Eds) (1996) *The Troubled Helix: Social and Psychological Implications of the new human genetics.* Cambridge University Press, Cambridge

MARTIN R.J. (1983) *A skill and strategies handbook working with people* . Spectrum, Prentice Hall.

McKISSOCK M (1995) *Coping with Grief.* Australia

MINNICK et al. (1994) *A Time to Decide, A Time to Heal.* Pineapple Press, Michigan.

MUNRO E.A., MANTHEI R.J. SMALL J.L. (1983) *Counselling: a skilled approach* (revised edition). Methuen, N.Z.

MURRAY J and M.(1988) *When the Dream is Shattered*. Lutheran Publishing House.

NANDA R. (1994) *Loss and Bereavement in Childbearing.* Blackwell Scientific Publications.

HOONAN E.(1983) *Counselling young people*. Methuen, USA.

NICOL J. (1997) *Loss of a Baby: Understanding Maternal Grief.* BANTAM Books.

OKUN B.F. (1976) *Effective helping: interviewing and counselling techniques.* Wadsworth Publishing, California.

PERLMAN E. (1957) *Social casework: a problem solving process.* Uni. of Chicago Press.

RAFAEL B. (1992) *The Anatomy of Bereavement, A_Handbook for the Caring Professions.* Routledge.

RODIN J, COLLINS A. (Eds). (1991) *Women and new Reproductive Technologies, Medical. Psychosocial, Legal and Ethical Dilemmas.* Lawrence Erlbaun Associates.

SANDS NSW. (1994) *Appropriate Care for Women and their Partners when their baby dies.* (Resources for health professionals caring for those who experience miscarriage, stillbirth, neonatal and infant death). Sydney.

SANDS VIC. (1987) *Your baby has died. A Guide for Parents whose baby has died before during or soon after birth.* Victoria.

SCHIFFMAN M. (1983) *Gestalt self therapy.* Self Therapy Press, USA.

SCOTT PECK M. (1986) *The Road Less Travelled.* Rider & Co.

SHEERM P.W., WHITE K.D. (1976) *Behaviour modification in Australia.* Australian Psychologist II, Monograph Supplement No. 3.

TRUAX C.B., CARKHUFF R.R. (1967) *Towards effective counselling and psychotherapy.* Aldine Publishing, Chicago.

WARLAND J. (1996) *Pregnancy After Loss.* Australia

Family interviewing:

BURNRM J.B. (1986) *Family therapy.* Tavistock, USA,

HARTMANN A., LAND J. (1983) *Family centred social work practice.* Free Press, USA.

RAYLEY J. (1985) *Problem Solving Therapy.* Harper, USA.

HILTON P S. (1993) *Counselling Parents of Children with Chronic Illness or Disability.* British Psychological Society.

MINUCHIN S. (1977) *Families and family therapy.* Social Science Paperback, UK.

SATIR, V. (1967) *Conjoint Family Therapy.* Science and Behaviour Books, USA.

SIMONS R. (1987) *After the Tears, Parents Talk about Raising a Child with a Disability.* The Children's Museum of Denver.

SKYNNER R.(1991) *Frameworks for viewing the family system.* Brunner/Mazel.

Genetic Counselling:

BIESECKER B, MAGYARI P A, PAUL N W (eds). *Strategies in Genetic Counselling, II. Religious, Cultural and Ethnic influences on the Counselling Process.* March of Dimes of Birth Defects Foundation, 1987. 23:6: 1-281.

CLARKE A. (1991) *Is non-directive Genetic Counselling Possible*? Lancet. 338(8773) 998-1001.

CLARKE A. (1995) *Genetic Counselling. Practice and Principles*. Routledge.

EMERY A H, PULLEN I M et al. (1984) *Psychological Aspects of Genetic Counselling.* Academic Press.

EVERS-KIEBOOMS G. ET AL (Eds.) (1992) *Psychosocial aspects of genetic counselling.* Birth Defects: Original Article Series (March of Dimes) 28, No. 1, Wiley Liss.

FINE et al. (1990) *Strategies in Genetic Counselling Reproductive Genetics and new Technologies.* March of Dimes Birth Defects Foundation, Birth Defects: Original Article Series, Vol 26, No. 3.

FRETS PG and NIERMEIJER MF (1990) *Reproductive planning after genetic counselling: A perspective from the last decade. Clin Genet* **38:** 295-306.

INATI M N, LAZAR E C, HASKIN-LEAHY L. *The Role of a Genetic Counsellor in a Perinatal Unit.* Seminars in Perinatology. 18:133-139.

KELLY P. (1977) *Dealing with dilemma: a manual for genetic counsellors.* Springer Verlag (ISBN 3540 902 376).
(This book presents some similar cases and also deals with the actual role of the genetic counsellor as part of the genetics team.)

KESSLER S. (1979) *Genetic Counselling, Psychological Dimensions*. Academic Press.

KESSLER S, LEVINE E. (1987) *Psychological Aspects of Genetic Counselling IV. The Subjective Assessment, of Probability.* Am. J. Med. Gen. 28: 361-170.

KESSLER S (1989) *Psychological aspects of genetic counselling VI. A critical review of the literature dealing with education and reproduction.* Am J Med Genet 34: 340-353

KESSLER S (1981) *Psychological aspects of genetic counselling: Analysis of a transcript.*

Am Journal Med Genet 8: 137-153

KESSLER S, KESSLER H and WARD P (1984) *Psychological aspects of genetic counselling, III, management of guilt and shame.* Am J Med Genet 17: 673-697

LEONARD and BLACK. (1984) *Decision-Making Dilemmas in Genetic Counselling*. Birth Defects 20:63-69.

LIPMAN-HAND A and CLARK FRASER F (1979) *Genetic counselling - the post counselling period: Parents' Perceptions of uncertainty*. Am J Med Genet 4: 51-71

LIPMAN-HAND A and CLARK FRASER F (1979) *Genetic counselling - the post*

counselling period: II. Making reproductive choices. Am J Med genet 4: 73-87

MARKS J.H. ET AL (Eds.) (1989) Genetic counselling, principles in action: A casebook. *Birth Defects: Original Article Series (March of Dimes)* 25, No. 5., Wiley Liss**.**
(This is an excellent book of cases seen by genetic counsellors often in conjunction with a clinical geneticist. Some of the cases read like long case presentations required by the HGSA Board of Genetic Counselling. The cases are of clinical genetic problems but discussed from a counselling viewpoint.)

MURRAY RF (1976) *Psychosocial aspects of genetic counselling*. Social Work in Health Care 2 (1): 13-23

RESTA R, EDITOR (2000). *Psyche and Helix. Psychological aspects of genetic counselling*. (Essays by Seymour Kessler). New York, Wiley Liss.

RONA R J, BEECH R, MANDALIA S, DONNAI D, et al. (1994) *The Influence of Genetic Counselling in the Era of DNA Testing on Knowledge, Reproductive Intentions and Psychological Wellbeing.* Clinical Genetics 46:2:198-204.

TARGUM SD (1981) *Psychotherapeutic considerations in genetic counselling . Am J Med Genet* 8: 281-289

WOLFF and JUNG. (1995) *Nondirectiveness and Genetic Counselling.* J. Gen. Couns. 4:3~26

ZELLERS *N J.* (1989) *Strategies in Genetic Counselling* (Vol 2) Human Sciences Press.

In addition, The Journal of Genetic Counselling is essential reading and often has useful references. It should be easily accessed from one of the Genetics Units.

Pineapple Press publishes some useful booklets on maternal loss and grief. The books are distributed through:

Capers Bookstore
47 Arthur Street
RED HILL Qld 4059
Tel: (07) 3369 9200
Fax: (07) 3369 9299
Ring or write for a catalogue

For the most up-to-date Genetics articles, access to Medline is essential. Ask your local library, the state library in your state, or one of your more fortunate colleagues to do a search for you. Inter-library loans will take about two weeks to be processed.

In addition, support group literature is often very instructive in terms of patient and parental response to living with genetic conditions.