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Genetic Counseling Program and Professional Society in Taiwan

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Greetings from Taiwan



Taiwan: an island on the west of the Pacific rim, the southeastern coast of mainland Asia.

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About Taiwan

- population of 23 million
- 213,598 newborns in 2015
- 507 hospitals and 20,628 clinics
- low birth rate, rapid aging
- The Genetic Health Act was legislated in 1984
- National Health Insurance coverage 99.6%

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Genetic Services

Since 1995, the nation-wide NHI program has provided full coverage of regular prenatal examinations. Bureau of Health Promotion supports the cost of genetic screening tests, these include amniocentesis, newborn screening programs, premarital physical examinations, and molecular tests of selected metabolic diseases through the newborn screening program, thalassemia and high incidence genetic diseases.

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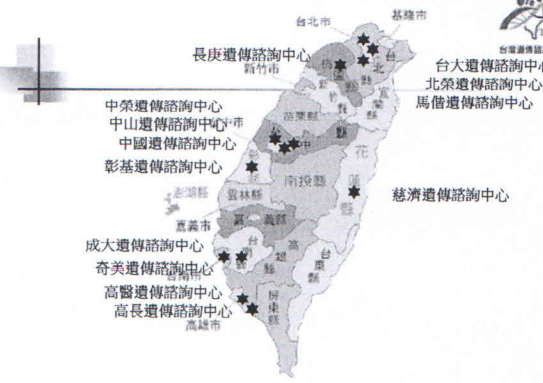
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Genetic Counseling Centers

- a total of thirteen Genetic Counseling Centers have been approved
- employ at least two physicians, pediatric and/or obstetric, two genetic counselors, three technicians (cytogenetic, biochemical, molecular) dietician, social worker, psychologist, rehabilitative therapist


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長庚遺傳諮詢中心 (新竹市)
中榮遺傳諮詢中心 (台中市)
中山遺傳諮詢中心 (台中市)
中國遺傳諮詢中心 (台中市)
彰基遺傳諮詢中心 (彰化縣)
成大遺傳諮詢中心 (台南市)
奇美遺傳諮詢中心 (台南市)
高醫遺傳諮詢中心 (高雄市)
高長遺傳諮詢中心 (高雄市)
慈濟遺傳諮詢中心 (花蓮縣)
台大遺傳諮詢中心 (台北市)
北榮遺傳諮詢中心 (基隆市)
馬偕遺傳諮詢中心 (台北市)


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Taiwan Foundation for Rare Disorders

- TFRD is a non-governmental organization, which advocates for patients' right and promotes benefits for people with rare diseases.
- In 2000, the Rare Disease Control and Orphan Drug Act was legislated for the specific care of people with rare diseases.


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Newborn Screening

In 1984, the Bureau of Health Promotion (BHP) launched a subsidy of newborn metabolic disorder screening program for congenital hyperthyroidism, phenylketonuria, homocystinuria, galactosemia, and glucose-6-phosphate dehydrogenase. In 2006, this program expanded to include 11 congenital metabolic diseases.


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Genetic Professional Education

- Training courses for nurses and doctors supported by MOHW.
- 2002~2004 the Institute of Genome Sciences, National Yang-Ming University offered training courses.
- 2003, National Taiwan University started to deliver a masters level program on genetic counseling for full-time.


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Support Groups

- Foundation for Rare Disorders
- Down Syndrome Foundation
- Thalassemia Association
- Hemophilia Association
- Marfan Syndrome Association
- Tourette Syndrome Association
- PKU, MPS, Prader-Willi Association
- Muscular Dystrophy, Spinocerebella Ataxia etc.

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Genetic Professional Organization


Taiwan Association of Genetic Counseling

<http://www.taiwangc.org.tw>

tagc.tagc@gmail.com

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Missions

1. Preserve and enhance the privilege of genetic counseling professionals
2. Represent and express the opinion of the members
3. Keep and promote the ethics of genetic counseling
4. Sponsor on-job training and continuing education for genetic counseling professionals
5. Supervise genetic counseling affairs and improve benefit


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Missions

6. Research on the development of genetic counseling
7. Issue the publications of genetic counseling
8. Enhance the cooperation between national and international genetic counseling organizations
9. Provide service to governmental institutions and members of the association
10. Other business assigned by relevant laws

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Members

- numbers: around 119
- Employment: Genetic Counseling Center, Private Prenatal Services, Assistant researcher, Laboratory Services, Other related fields

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Activities

- Semi-annual (spring, fall) conference since 2008
- Certification of genetic counselors started in 2009, now 61 persons certified.
- Participated activities with other patient groups and professional societies for promote genetic counseling.

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Future Plans/Challenges

- To facilitate members' genetic counseling competence
- To advocate genetic counseling among patients and the public
- To promote professional development opportunities
- To build licensure for genetic counselors.


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Genetic Counseling Program
National Taiwan University




- master-level genetic counselling program since 2003
- Student Number enrolled 13 per year
- Undergraduate backgrounds


graduate from a university majored in life science or related field, including medicine, nursing, medical technology et al.

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Faculty




- Medical Geneticist
- Psychologist
- Nursing
- Genetic Counseling
- Epidemiologist
- Clinical coordinator

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Curriculum I




- for graduation, a total of 22 required credits and 2 elective credits, 6 credits thesis.
- Medical Genetics Symposium (II) as a mandatory course.
- Molecular genetic, cytogenetic, prenatal genetic clinic, and clinical internship training.
- The minimum total number of internship (including clinical and laboratory) is at least 300 hours for certification of a genetic counselor.

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Curriculum II




- Human Embryology and Birth Defects
- Introduction of Psychology
- Introduction to Medical Genetics
- Seminar on Medical Genetics I
- Psychosocial Impact of Genetic Disorders
- Theory and Skills of Counseling
- Statistical Genetics and Research Methodology

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Curriculum III



- Medical Genetics (I)
- Seminar on Medical Genetics (II)
- Seminar in Inborn Errors of Metabolism
- Laboratory in Molecular Genetics
- Clinical Training in Prenatal Genetics
- Introduction of Molecular and Cellular Biology
- Laboratory in Cytogenetics
- Clinical Training in Clinical Genetics
- M.S. Thesis

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Genetic Counseling Graduate

Many of these graduates were supported by their current institutions while they completed training and were then hired as genetic counselors by their supporting program. Others have found jobs in GCCs, private prenatal service providers, laboratories or other related organizations


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Master Thesis I

- Genetic Knowledge, Attitude and Educational Needs of Clinical Nurses of a Hospital in Central Taiwan
- Factors Affecting Women's Acceptance of Amniocentesis and the Effectiveness of the Genetic Counseling
- The Concerns and Coping Behaviors of Achondroplasia Patients and Their Mothers
- Parental Stress and Quality of Life in Parents of Turner Syndrome Patients


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Master Thesis II

- Psychological Adaptation and Decisional Conflict in Late-onset Hereditary Neurodegenerative Disease Family
- Effect of Genetic Counseling on Alleviating the Anxiety of Family with Newborn Screening Positive Infants: A Study of G6PD Deficiency
- Parental Stress and Rearing Practice in Mother of Children With Inherited Metabolic Disease


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Master Thesis III

- The Effect of Maternal Rearing Practice on Temperament and Dietary Control in Children with Phenylketonuria
- Pregnant Women's Attitude Towards Carrier Testing for Fragile X Syndrome: An Application of Health Belief Model
- Uncertainty and Coping Style of Patients with Neurofibromatosis Type 1

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Thank you for your attention!

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