PERSPECTIVES

IN GENETIC COUNSELING

A NEWSLETTER OF THE NATIONAL SOCIETY OF GENETIC COUNSELORS
Volume 2, Number 2, June 1980

MANIC DEPRESSIVE ILLNESS: A COUNSELING AND EDUCATION PROGRAM FOR PATIENTS AND THEIR SPOUSES. Donna Feigin, M.S.

Last fall, I had the opportunity to work at a clinic for manic-depressive patients. Under the title of research assistant I served as the genetics consultant on a team of psychiatrists, psychologists and nurses. Our responsibility was to create and design studies which dealt with facets of manic depressive illness and to provide our subject population with medical and pharmaceutical care. Despite several obstacles such as the lack of funds and the rapid turnover of staff, I managed to become involved in several projects during my brief stay, the most interesting of which was a counseling/education program for patients and their spouses.

In speaking with the patients, it was apparent that many of them could benefit from group counseling. Psychological therapy was not included in their treatment since the clinic's orientation was the use of drug therapy. Like parent groups and other societies which focus on a common problem, a counseling group would be a vehicle for our patients to meet each other, vent and compare their problems and gain support, knowledge and perspective of this complex and poorly understood illness.

A psychologist, psychiatric nurse and I designed a four-part program as a service to the patients and as an experimental supplement to their treatment.

Our clinic population consisted of 200 men and women between the ages of 20 and 65 who suffered from an affective (mood) disorder, the most common of which is manic depressive illness (MDI). People with MDI experience extreme mood swings which may last a few days to weeks, followed by symptom-free intervals. There is no personality deterioration between or after these episodes. MDI may be bipolar (patients who experience both high and low moods) or unipolar (extreme lows only). A "high" or manic episode is characterized by elation, hyperactivity and flight of ideas, often accompanied by the making of excessive plans, reduced need for sleep and increased libido. A "low" denotes depressed mood, loss of energy and interest, poor apetite, sleep difficulty, feelings of self-reproach, and so on.

The affective disorders exclude schizophrenia, an illness characterized by thought disorder, hallucinations, flat affect and deterioration of personality over time. (continued on page 2)

CERTIFICATION OF GENETIC COUNSELORS

The American Board of Medical Genetics (ABMG, Inc.) was incorporated in 1980 to provide accreditation of training programs and certification of individuals who provide medical genetic services.

Certification is available for six subspecialties: Clinical Geneticist; Ph.D. Medical Geneticist; Clinical Biochemical Geneticist; Clinical Cytogeneticist; Clinical Immunogeneticist; and Genetic Counselor. Brochures regarding the certification procedure, eligibility and examination information will be sent to registered members of the American Society of Human Genetics and the National Society of Genetic Counselors. Copies can also be requested from:

American Board of Medical Genetics, Inc.
c/o David Rimoin, M.D., Ph.D.
Harbor-UCLA Medical Center
Division of Medical Genetics
1000 West Carson Street
Torrance, California 90509

The task of designing a Board Examination is formidable as well as expensive. The National Board of Medical Examiners has been contracted by the ABMG, Inc. for services necessary for preparation and administration of the examination. Eligible candidates will be required to successfully complete a two part examination: Part I (General Genetics) and Part II (Subspecialty examination).

There is a considerable cost associated with developing the number of examination formats necessary for all subspecialties. It is anticipated that the cost for Board Certification will be approximately $500 ($200 application fee and $300 for examination (Part I and Part II). A number of Genetic Counselors have expressed considerable concern to ABMG Board members regarding the magnitude of the cost for the Genetic Counselor Subspecialty. As members of the ABMG, Inc. we want you to know that the entire Board is acutely aware of this concern and recognizes the range of salary levels of professionals involved with the delivery of genetic services. The Board is actively committed to seeking a means of adjusting the fees for the Genetic Couselor Subspeciality. At present three alternatives are being considered: (continued on page 5)

Publication of **Perspectives in Genetic Counseling** is supported in part by a grant from the March of Dimes-Birth Defects Foundation

Subjects

Our first group comprised a subpopulation which met the following additional criteria: they were married to unaffected persons, were bipolar, and their conditions were currently stabilized by Lithium treatment. These qualifications were imposed in order to reduce experimental variability in analyzing the results and to maximize the amount of common experience among the participants with respect to diagnosis, treatment and social life.

The age range was 30 to 65, median age 38. All the participants were intelligent, articulate, open and motivated.

Methods

Letters were sent to three couples inviting them to take part in a four-session counseling/education program on Monday evenings from 7 to 8:30. The invitation included a brief syllabus: "Session I: Mania and Depression - Cause, Course, and Effects, Session II: Treatment of MDI, Session III: Genetics of MDI, and Session IV: Open Discussion, Summary and Evaluation". Sessions I - III were chaired by the psychologist, nurse, and genetic counselor respectively. The last session had no formal chairperson.

Each session consisted of a 20-40 minute lecture followed by an open discussion. To assess the educational aspect of the sessions, a 15-item questionnaire was administered before the first and after the last meeting. To assess the counseling aspect, we had planned to administer a marriage questionnaire compiled from a number of psychological and sociological studies of the dynamics of communication between husband and wife.

Session I, our general introduction to the series and to each other, served to break the ice for subsequent sessions. A brief overview of MDI including its definition and history was presented. The psychologist then raised several issues and asked for reactions from the participants. Some of the issues discussed were: 1) the lack of public interest and education about MDI as a biochemical disorder; 2) feelings of guilt and anger of both patient and spouse; 3) feelings about having children; 4) fears and fantasies related to MDI; and 5) the significance of group counseling.

Session II traced the history of treatment of MDI beginning with the serrendipitous discovery that electroconvulsive therapy, also known as ECT or shock treatment, has calming effects on manic patients. Although the precise mode of action is unknown, ECT is effective in controlling manic episodes. The main disadvantage is that it does not consistently prevent subsequnt episodes nor does it alleviate depression. In contrast to ECT, lithium carbonate is prophylactic in that it reduces the frequencey, depth and duration of future manic and depressive episodes.

Session III, Genetics, progressed from basic mendelian inheritance to theories of modes of inheritance of MDI. One week prior to the session, the participants received a list of 20 genetic terms. The list defined gene, chromosome, autosome, sex chromosome, polygenic, multifactorial, dominant, MZ vs. DZ twins, and so forth. In addition, each received a set of 12 charts and diagrams to help clarify and summarize the lecture. The diagrams, in order, depicted meiosis and fertilization, a pair of chromosomes, the characteristics of autosomal dominant traits, recessive inheritance, pedigrees, evidence of genetic etiology of MDI, polygenic inheritance illustrated in a pedigree, and a karyotype with banded chromosomes.

Topics covered, after a preliminary discussion of basic human genetics, were; 1) Evidence of a genetic component in MDI; 2) The risk of transmitting MDI; and 3) Theories of the mode of inheritance of the disorder. Three lines of evidence lead one to suspect that MDI is at least in part genetic. Twin studies show a 69% concordance rate of MDI among nearly 100 pairs of MZ twins, compared to a 13% concordance rate among over 200 pairs of DZ twins. Of 12 pairs of MZ twins reared apart, 8 pairs (67%) were concordant for MDI (2). Secondly, a study of biological and adoptive parents of manic-depressives in Belgium where adoption records are open, showed that significantly more biological parents were similarly affected than were adoptive parents (1). Thirdly, family studies revealed that near relatives of patients were more often affected than were distant relatives, and the latter had a higher incidence of MDI than the general population(3).

Regarding the risk of inheriting the illness, a large number of studies conducted all over the world in the last 40 years suggest that if one parent is affected, there is a 10-15% risk that any of his children will be affected. When one parent and one child are affected, the risk to any other child in the sibship increases to 26%, and to 43% when both parents are affected (3).

The last segment of the lecture weighed the evidence for and against each of three possible modes of inheritance: Autosomal Dominant with incomplete penetrance, polygenic inheritance and multifactorial inheritance.

Results and Discussion

As a service to the patient and spouse, the experiment proved successful. All the participants felt that they gained from the experience in practical knowledge as well as psychologically. The group members exchanged phone numbers and planned to continue to meet on their own. They claimed to have gained insight into their own condition, support from others in the same situation, and a better perspective of how the illness affects their spouses.

As an experiment, several features were lacking. We did not assess the marriage questionnaire meaningfully. Our sample was much to small to determine whether the information dispensed was absorbed and retained. A compilation of results from many groups such as this one is necessary before any conclusions can be reached. A lack of funding resulted in the premature termination of a potentially workable program (albeit in need of refinement and stricter organization) which could contribute much to the patients as well as to the existing body of knowledge of MDI.

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NEWS FROM THE REGIONS

REGION I

A questionnaire has been sent to all members regarding plans for a regional meeting. The dates for this meeting have been set for September 4-5, 1980. Program content, location, costs and other details have not yet been finalized but will be announced by mail very soon. If any of you New England members did not receive the planning questionnaire, please contact Stacey T. Kacoyanis, Genetics Unit, Mass. General Hospital, Boston, MA 02114 (617) 726-3824.

REGION II

Our second district meeting was held April 19 at Morristown Memorial Hospital with approximately 30 in attendance. This meeting was in a workshop format with participants choosing 2 of the following topics: Roles and Skills of the Genetic Counselor, Parent Groups, Prenatal Diagnosis-New Indications, Dealing with Fatal Disease, Legal Responsibilities, Clinical Research and The Counseling Setting/Satellite Clinics. These topics prompted lively discussions and allowed for exchange of mutual problems and solutions. The wide variety of job settings, duties and roles was impressive.

Four invited presenters gave short talks on projects they have undertaken. Luba Djurdjinovic outlined a method of genetic risk scoring to be used by family planning workers to assess the need for Genetic Services. This method is used by non-genetic counselors to screen family planning clients. Those identified as needing further intervention are referred to the nearest Genetic Service Unit. Eugene Trabilcy presented a pedigree form that he has found useful. Doris Kramer outlined the Genetic Services Program of the state of New Jersey for which she serves as program assistant and works in the areas of planning, education and service.

Kathi Hanna Mesiron discussed a project developed by Sarah Lawrence students to standardize risk figures quoted at aminocentesis counseling. The Sarah Lawrence students involved on the project have been frustrated by the difference in figures used among their field placements. They developed a questionnaire to survey a selected number of centers in the area. They have met with some resistance to the project but hope they will have results compiled in the near future.

Ginny Corson presented an update on the society's activities. One controversial item was the proposed $600 fee to take the accreditation exam. The members present felt this was exhorbinant and that we should ask our representatives to begin speaking out against this large a fee.

REGION V

Plans for the Region V meeting on July 18-19 are in the final stages. The program format was designed after careful review of the opinions expressed on the previously distributed questionnaire. Program topics will include: interviewing techniques; crisis intervention; update on hemoglobinopathies; professional burn-out; a review of educational materials and programs; professional issues; and utilization of community resources in the genetic counseling process.

REGION VI

A regional meeting is planned for July 25-26, 1980. In response to suggestions approved at last year's meeting, this meeting will include workshops, original paper presentations, and featured speakers. Workshop topics will be: prenatal diagnosis counseling, clinic coordination and administration aspects of the gentic counselors role. The selected speakers, Audrey Heimler and John Carey, will discuss "The Art of Genetic Counseling". Funding is being sought to defray expenses to members planning to attend, and further details will be circulated to Region VI members.

CERTIFICATION, continued

1. Application for grant funds to assist in the development of the Genetic Counselor subspecialty Board Examination. This would effectively reduce the examination cost for Genetic Counselors. The National Board of Medical Examiners is aware of agencies who may be willing to support the development of a testing tool for this subspecialty.

2. Adjustment of fees on the basis of the number of individuals who register for the Board Examination. An initial survey through the ASHG indicated only 79 Genetic Counselors interested in certification. However, on the basis of NSGC membership we believe that a much larger number of individuals will seek certification. Thus, if a large number of Genetic Counselors apply and are eligible for certification, the cost could be reduced.

3. Recognizing the differential in salaries, a lower fee for the Genetic Counselor subspecialty may be set.

As members of the American Board of Medical Genetics, Inc., we will continue to try and represent the feelings of our Genetic Counselor collegues on this issue. Certification is a very necessary step toward the advancement of our profession and we urge all of you to apply.

Ann C. M. Smith, M.A. (Secretary)
Audrey Heimler, M.S.
Board of Directors
American Board of Medical Genetics, Inc.

Deborah L. Eunpu, NSGC
Clinical Genetics Center
Children's Hospital of Philadelphia
34th and Civic Center Boulevard
Philadelphia, Pennsylvania 19104

MANIC DEPRESSIVE ILLNESS, continued

References Cited

1. Mendlewicz, J. Adoption studies supporting genetic transmission in manic depressive illness. **Nature** 268: 327-329 1977.

2. Tsuang, M.T., Genetic counseling for psychiatric patients and their families. **Am J. Psychiatry** 135 (12): 1465-75, 1978.

3. Winokur, G., Clayton, P. Family history studies. I. Two types of affective disorders separated according to genetic and clinical factors. **Recent Advances in Biol. Psychiat.** 9:35-50, 1966.

EDITORIAL NOTE

In order to meet the growing needs and interests of Society members, **Perspectives in Genetic Counseling** will be expanding in the coming months. While the format and purpose will remain similar, new features will include book reviews, a correspondence section and articles on selected topics.

Individuals interested in contributing an article, original research paper or case report should contact the Editor regarding specific guidelines for manuscripts. Those wishing to submit a letter concerning issues of relevance to Society members should submit them directly to the Editor. Letters should be typed and doubled spaced throughout with name and full address.

To facilitate this expansion, an Editorial Board will be established. Individuals who would like to work on the staff should write to the Editor stating specific areas of interest and some background information regarding past writing experience. Those who have already expressed an interest in working on **Perspectives** will be contacted in the next few months and need not write again.

ASHG AND NSGC ANNUAL MEETINGS

The thirty-first annual meeting of the American Society of Human Genetics will be held at the New York Hilton Hotel (Rockefeller Center) September 24-27, 1980. Requests for registration materials should be addressed to:

ASHG Local Arrangements Committee
Mailbox 64
Babies Hospital
3959 Broadway
New York, N.Y. 10032

A late fee will be added for those registering after August 1, 1980.

The National Society of Genetic Counselors, Inc. will convene for its annual business meeting on September 24, 1980 from 5-7 P.M. in Gramercy A in the hotel.

NATIONAL CONFERENCE ON MATERNAL SERUM ALPHA-FETOPROTEIN

The National Center for Health Care Technology and Food and Drug Administration of the Public Health Service, Department of Health and Human Services, are sponsoring a national conference on "Maternal Serum Alpha-Fetoprotein: Issues in the Prenatal Screening and Diagnosis of Neural Tube Defects." The conference will be held on July 28 - 30, 1980 at the Shoreham Hotel, Washington, D.C.

Maternal Serum Alpha-Fetoprotein testing is a new technique that offers prospective parents the opportunity of detecting severe fetal neural tube defects in time to offer them the option of preparing for the birth of an affected child or terminating the pregnancy. The detection of an affected fetus requires not only the serum AFP testing, but a carefully coordinated series of diagnostic steps. The conference will focus on the medical, legal, ethical/social, and economic issues of MSAFP.

The conference is designed for providers of prenatal and neonatal care, genetic counselors, pathologists, state and local Health Department personnel, Health Services administrators, laboratory personnel, pharmaceutical companies, consumers, and special interest groups.

For further information, please contact Ms. Hope Sayles, Koba Associates, Inc., 2000 Florida Avenue, N.W., Washington, DC 20009, (202) 328-5739 or 75.

ERRATA

In the last issue of **Perspectives in Genetic Counseling** the address for Ann Walker, chairperson of the Social Issues Committee was incorrect. The proper address for correspondence follows:

Division of Medical Genetics
University of California
Irvine Medical Center
Mail Route 81
101 City Drive South
Orange, Ca. 92668

NOTICE

As coordinator of the newborn metabolic screening program for the state of Washington, I am interested in sharing concerns and problems with individuals in similar positions in other states. Possibly, a meeting will be arranged during the 1980 ASHG meeting. Please contact:

Marsha Wolf, M.S.
Genetics Program
1704 N.E. 150th Street
Seattle, WA 98155
206-545-6783.

POSITIONS AVAILABLE

Genetic Counselor

An experienced genetic counselor is sought by the San Jose Hospital to organize and participate in a new prenatal diagnosis program which is scheduled to commence July 1, 1980. Inquiries should be addressed to:

John D. Stephens, M.D.
San Jose Hospital
675 East Santa Clara
San Jose, CA 95112
Phone: 408-998-3212

Genetic Counselor/Clinic Coordinator

To coordinate activities of five genetic consultants throughout Iowa. M.S. in Genetics or education plus appropriate experience required. Position will be available July, 1980. Address inquiries to:

James Bartley, M.D., Ph.D.
Division of Medical Genetics
Department of Pediatrics
University of Iowa
Iowa City, Iowa 52242
Phone: 319-356-2674

Genetic Counselor

To work as Albemarle Regional Genetic Consultant serving 10 counties in Northeastern region of North Carolina. A Master degree in genetic counseling and 1-2 years of experience are required. Address inquiries to:

Elizabeth Moore
Division of Health Services
Department of Human Genetics
P.O. Box 2091
Raleigh, N.C. 27602
Phone: 919-733-7437

Genetic Associate

A position for a GENETIC ASSOCIATE is available within the Division of Human Genetics, Children's Hospital of Buffalo. M.S. in Genetic Counseling and/or equivalent experience are required. This is an excellent opportunity to work within an active clinical and research program and includes outreach and educational acitvities. Please submit your curriculum vitae and the names of three references to R.M. Bannerman, M.D., Director Division of Human Genetics, Dept. of Pediatrics, SUNYAB, Children's Hospital of Buffalo, 219 Bryant Street, Buffalo, N.Y. 14222.

An Equal Opportunity/Affirmative Action Employer

Genetic Counseling Associate

Shodair-Montana Regional Genetics Program.

Applications are being solicited for a position of Genetic Counseling Associate/Clinical Coordinator of the Genetics Unit and the Regional Genetics Program at Shodair Children's Hospital, Helena, Montana. Clinical activities involve a general genetic clinic, field clinic, a prenatal diagnosis unit, regional intersex and skeletal dysplasia centers, and field work with Hutterites and Native Americans. Academic affiliations are with the University of Washington/Seattle, and Montana State University at Bozeman.

The position will be open on or after 1 August 1980. Salary is negotiable. Costs for interviews and moving will be paid.

Interested persons should contact the Chairperson of the Search Committee, Dr. John M. Opitz, Shodair Children's Hospital, Box 5539, 840 Helena Avenue, Helena, MT 59601.

Shodair Hospital is an Affirmative Action/Equal Opportunity employer.