PERSPECTIVES
in Genetic Counseling

newsletter of the National Society of Genetic Counselors, Inc.

Vol. 10 No.1 Spring 1988

New Orleans is Conference Site

NSGC's 8th Annual Education Conference will be held October 9 - 11 at the Hyatt Regency in New Orleans. The program, "Strategies in Genetic Counseling: Political Influences from Society to the Workplace," will focus on the effect of outside influences on the workplace, with a special emphasis on the political survival of the genetic counselor.

Abstracts are being accepted through May 1. Detailed information and registration materials will be mailed to the membership in early May.

on the inside

The NSGC gratefully acknowledges Integrated Genetics' support of this issue of *Perspectives*.

INTEGRATED GENETICS

Genetic Counseling in Foreign Lands

Genetics in Morocco

by Anne Matthews, R.N., Ph.D.
American Consulate, Casablanca

Morocco, like many other third world countries, has its health care priorities elsewhere. And, perhaps, that is appropriate in light of its current level of development.

Caught between its traditional Islamic values and modern technology, Morocco must direct its major health care focus in two areas: 1) decreasing the prevalence of parasitic and infectious diseases among its 22 million people and 2) instituting a country-wide family planning program.

Measles, polio and tuberculosis are common as are hepatitis, typhoid and rabies. The director of a local school for the blind stated that a major cause of blindness at his institution was *in utero* exposure to measles. In order to combat this problem, the government has instituted a national educational and service

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An Experience in West Africa

by Kurt Fenolio, M.S.
San Francisco General Hospital

For a period just short of two years, I took "time out" from the world of genetic counseling and participated in a health service project in a rural area of Burkina Faso in central West Africa, a country about the size of California. The goal of the project was to train 16 volunteer village health care workers in first aid and health education, especially in activities related to hygiene and nutrition.

Armed with a few lessons in first aid and a few basic supplies, the volunteers set up small huts as "health centers" in their home villages. These centers would serve as first aid posts and as triage sites for the regional health centers about 15 kilometers away.

Few men in these remote villages have a basic education, and only a few children in a given family can attend school

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Prevention of Genetic Diseases in Cuba

by Victor B. Penchaszadeh, M.D., M.S., Beth Israel Medical Center, New York

I had the opportunity to evaluate the medical genetics program in Cuba on behalf of the World Health Organization during two site visits in the spring and fall of 1987.

I visited several tertiary genetic centers across the country as well as small community based rural health centers. I witnessed individual and group counseling sessions for different prenatal and pediatric genetic problems and had extensive discussions with the directors of the program as well as with young medical geneticists.

In Cuba, there is a free national health care system run by the Ministry of Health, organized according to needs and available resources on a regionalized basis with primary health centers related to local and regional hospitals. The country has 10 million inhabitants, 165,000 annual births and an infant mortality of 13.6 per 1000. The ethnic composition of the population is primarily Spanish and Black with a high degree of admixture (mulattoes). The overall carrier frequency of the S mutation is about 0.05, making sickle cell the most common genetic disease in Cuba, with about 8000 affected

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Corner Thoughts

Last May, the first meeting of Canadian Genetic Counsellors/Associates was held in Toronto. The purpose of this meeting was to discuss the possible formation of a sister Canadian organization. The 51 participants represented genetics centres from Newfoundland to Vancouver.

The general consensus of the group was that a Canadian organization should be formed. The aims of this organization would be to foster continuing education, to explore national networking, to promote professional advancement and the delivery of genetic services and to establish reasonable salary levels.

These goals are similar to those of the NSGC. However, it was felt that a separate organization was necessary for a number of reasons: 1) many individuals in Canada who function as genetic counsellors/associates would not be eligible for full membership according to existing NSGC bylaws; 2) the Canadian health care system is entirely different from that in the U.S.A., creating unique concerns and problems; and 3) our legislative system is also different.

The formation of a sister Canadian group should not be construed as an attempt to disjoin from the NSGC. Rather it is a means of strengthening the profession in Canada and thereby bolstering support to the NSGC.

At the conclusion of the meeting, an Executive Board was formed consisting of Susan Creighton (Vancouver, B.C.), Zella Pyatt (Edmonton, Alberta), Louise Carriere (Sudburry, Ontario), and Mary Connolly (St. John's, Newfoundland). *CROSSOVER* was endorsed as the official newsletter of the organization. Bylaws are being formed for discussion at the next meeting (April 1988).

The input and past experiences of the NSGC have been extremely valuable in planning for a Canadian organization and have been most appreciated. The welcoming response which was received at the NSGC Education Meeting in San Diego was most encouraging. We look forward to a warm strong liaison with the NSGC in years to come.

Susan Creighton

Susan B. Creighton, M.S.
Grace Hospital, Vancouver, B.C.

Open Forum

Clastogenic Exposures on Family DNA Studies

by Gale B. Gardiner, M.S., Newington Children's Hospital, Newington, CT

An experience at the Newington Children's Hospital Muscle Disease Clinic with a family wanting molecular DNA studies for a pregnancy "at risk" for Duchenne muscular dystrophy has prompted me to question whether the information consistently gathered about the family members participating in such studies is extensive enough. The maternal grandfather of the fetus asked if the study results could be affected by his exposure to tetrachlorohydrate and sulfur dioxide. Knowing that RFLP techniques are sensitive to single base pair differences which could be caused by mutagenic or clastogenic agents, I had to withhold my reassurance.

Consider a situation in which such an exposure causes a base pair change at the DNA level: if by chance this change affects the RFLP pattern expected within a family, the results of that study could incorrectly be interpreted as a case of nonpaternity. Such a scenario could possibly result from a recent viral illness, X-irradiation or medications that induce clastogenic effects on the chromosomes.

Other potential causes for false nonpaternity interpretations from extended family studies could be the germinal mosaicism recently reported at the American Society of Human Genetics meeting in San Diego.[1]

The Baylor School of Medicine's Prenatal Diagnostic Laboratory reports nonpaternity in approximately 5% of the families and related that they were unaware that information on environmental exposures was consistently collected on extended family members used for such studies.

In view of this possibility, it may be prudent for genetic counselors coordinating extended family DNA studies to collect information on medical and environmental exposures of all family members participating in molecular DNA studies. It may also be of interest for the groups conducting the DNA studies to conduct retrospective studies on all "nonpaternity families" for medical and environmental exposure histories.

[1] Darras BT and Francke U, Male germline mosaicism for DMD deletion mutation: Implications for genetic counseling. AJHG, Vol 41 (3), 1987.

EdNotes

This issue of *Perspectives* is a landmark issue for three reasons: 1) it's the first "theme" issue; 2) it's expanded by 50% and 3) it's the first issue in a volume supported by Integrated Genetics.

Volume 10's exploration of *Genetic Counseling in Foreign Lands* features personal experiences with genetics in Morocco and West Africa, a report on genetic services in Cuba and a description of genetic counseling in the U.K.

Interpreters were necessary in both cases involving French and Chinese clients. (See *Case Reports.*) Susan Creighton reports on the development of a Canadian genetic counselors association in *Corner Thoughts.*

Family studies of genetic disorders in the United Kingdom are reviewed in *Book Bag* and even the *Bulletin Board* announces two workshops dealing with Haitian and Vietnamese clients.

Now *that's* international!

The production of this theme issue presented us with a dilemma. If we were to include these relevant contributions, we would need to expand to 12 pages. As editor of *Perspectives*, I couldn't have been happier. Finally, after all the requests by Debbie Eunpu, Joe McInerney, the Editorial Board and me for articles, the membership responded.

However, the expansion of *Perspectives* would entail additional publication costs. Bea Leopold, Diane Baker and I were struggling with how we could manage the budget when we were literally rescued by Integrated Genetics.

Integrated Genetics had expressed an interest months ago in supporting the NSGC's educational activities. When we presented them with our dilemma, they were quick to respond to this opportunity, offering to cover part of the expenses associated with Volume 10. Without this support, this year's budget would be seriously compromised. Therefore, on behalf of the NSGC, Diane Baker, Bea Leopold and I wish to thank Integrated Genetics for their generous support of *Perspectives*, without which this expansion wouldn't be easily possible.

The theme of the next issue is the *Politics of Genetics* and will introduce some topics that will be more thoroughly covered at the annual meeting in New Orleans this fall. The deadline for submissions is May 11. As always, your submissions are welcome. And thanks to Integrated Genetics, we now have plenty of room.

Ed Kloza

FEEDBACK

Case No. 8: *"... Group vs. Individual Counseling..." (Vol. 9 No. 3)*

The case presented by Adria Bowin raises an interesting question regarding amniocentesis counseling: *Is there something missing when the patient receives amniocentesis counseling in a group?*

I am thoroughly convinced that for most couples with no unusual family history who are referred for counseling because of maternal age ≥35 years, a group session is an ideal way to provide information. It allows the couple to see that there are other couples having children at later ages. It also provides a setting where everyone hears the answers to questions that they might not have thought of themselves. Many couples feel that the group session is a "normalizing" procedure. They do not feel singled out.

In direct response to the situation described in Case No. 8, our genetics center has a slightly different model for group counseling. Intake is done by telephone and patients with no indication for amniocentesis other than maternal age are signed up for a group.

We schedule 8-10 couples per group and the meetings are held in the evening to encourage both members of the couples to attend. The information session lasts 45-60 minutes and includes a discussion of the procedure, the risks and the meaning of abnormal results. Slides are used followed by a Q&A session. At the end of the class, we tell the participants that we need to meet with each couple individually for a few minutes, whether or not they have made a decision about the procedure. At this time, two other members of the genetics staff are made available to meet with the couples in the order in which they arrived at the class. When we meet with each couple, we ask if they have any questions, review the pedigree, discuss Rhogam™, if appropriate, and last but most important, we ask each member of the couple if they have discussed between themselves what they might do if an abnormality is detected following the amniocentesis. It is amazing how many couples say, "It will never happen to us, so we don't need to think about it now." If a couple takes this position or has not dealt with this issue, we encourage them to begin thinking of how they would react to such a situation.

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Case No. 10

Counseling a French Couple for a Variant of Tay-Sachs Disease

by Marie Barr, M.S., Thomas Jefferson University, Philadelphia, PA

Late last August, Mr. and Mrs. A and their young daughter, Sandrine, arrived in Philadelphia from the town of Trebes in southern France. A provisional diagnosis of Tay-Sachs disease had been made in their own country and the family felt they needed more information.

Sandrine was born September 20, 1984 and had a seemingly normal development until she was past her second birthday. In early 1987, problems with walking and behavior were first noticed. She was seen in Toulouse by a neurologist who reported an "ataxic" gait. Behavioral changes included replacement of early language by incomprehensible babble. There was a diminution of vision. Eye examination revealed a cherry red spot. Plasma and leukocyte lysosomal hydrolase analysis showed a low level of hexosaminidase A (hex A) and of total hexosaminidase, supporting (but not confirming) a suspicion of a gangliosidosis of the GM2 type. On a return visit in April she could walk only with support and her behavior had worsened. The physicians spoke at length with the family (who is not Jewish), giving them a provisional diagnosis of late onset Tay-Sachs disease with no hope of recovery and no available treatment.

Sandrine's parents appealed to the French Ministry of Health for further information but received no response. They then contacted the U.S. Embassy which informed them of the National Tay-Sachs and Allied Diseases Association (NTSAD) in this country. After much correspondence and many telephone calls to NTSAD, the family was convinced that further help was available in the U.S., even though they understood there was no cure or treatment for Tay-Sachs disease. Public donations and corporate support funded a trip for the family. A French teacher in Philadelphia volunteered to act as translator.

The evaluation at Thomas Jefferson University included a series of ophthalmological, neurological and biochemical tests, all of which were consistent with the diagnosis of "late onset Tay-Sachs."

The biochemical tests were significantly revealing. In the classic form of Tay-Sachs, the enzyme hex A is completely absent, and there is no activity when tested with either artificial or natural substrate (Gm2 ganglioside). In Sandrine's case, hex A activity using *artificial* substrate was present, although lower than normal. This led to the original diagnosis of "late onset." However, there was essentially no activity against the *natural* substrate, a finding characteristic of the B1 variant of Tay-Sachs.

These biochemical data are especially important for counseling in the event of another pregnancy. It is possible that Mrs. A (who is still young) may wish to have another child. If she had prenatal testing with either amniocentesis or CVS performed in the typical manner with the artificial substrate alone, misdiagnosis could easily occur. This was explained to the family, but another pregnancy was not under active consideration at the time. Reinforcement of this concept will be important at a later date.

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Case No. 11

Conflict between Ancient Culture and Modern Technology

by Ilana Mittman, M.S., San Francisco General Hospital

YW, a 37-year-old G4P3 Chinese woman, was referred for amniocentesis counseling. The session was conducted with the aid of a Cantonese interpreter. At the end of the session, YW stated that she would consider termination if the results were abnormal.

Several weeks later, she came for the procedure, again without her husband. The results of the amino revealed 47, XY, +21. We contacted the patient immediately to schedule an appointment to discuss the results. When we communicated the results through the interpreter, we learned that YW had recently emigrated from a small country village in Canton, China. She had three daughters and wanted a son; prenatal diagnosis in this pregnancy was requested to determine the sex of the fetus. We also learned that her family was dysfunctional and a referral had been made to Children's Emergency Services.

YW came in for counseling with her husband. We discussed the diagnosis and the

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Case No. 10: Counseling a French Couple for a Variant of Tay-Sachs Disease, from p. 3

Tone of voice, facial expression and body language become most important when counseling via an interpreter. Other than learning that Mrs. A has a normal eight-year-old girl from a previous marriage, little family information was available from them. The president of NTSAD was present for several sessions with the family, not in an official capacity, but as a mother of a deceased Tay-Sachs child. This was one of the most valuable and warmest associations for Mrs. A—someone who had an experience similar to her own.

By the third day, the test results were available and explained to the family. Sadly, the prognosis was the same as the one they had received in France months before, but this time the family was surrounded by supportive and caring people. The family again described what they had first faced in France...rejection, no offers of help, no advice, no information and no one to turn to. Here, their confidence had been gained and they were able to be more accepting of the diagnosis and begin to deal with it. They began to ask questions: *What about her swallowing difficulties? Does she need special food? Does she need an oxygen tank? Will death occur while she sleeps? Will she have pain?* These questions could be answered only in part, but the family now knows that they have a resource.

Mrs. A was even able to think beyond Sandrine. She asked about the carrier status of her other daughter and how she could be tested. Her last concern, and one she continues to pursue, is what she can do to help others in her country who might be in similar situations. Toward the end of the sessions, we discussed continuing support. The family understands that they may call on us any time.

This case demonstrates some important counseling issues: the need for accurate diagnosis, the need to establish rapport through confidence, the value of peer support, the need for sustained follow-up and, most importantly, the need for counseling. Had the family had guidance and understanding initially, they would never have had to go to such extremes.

In December, we heard that Sandrine's condition was worsening. We were able to identify several agencies in southern France willing to assist the A's with their continuing problems. In January, we were approached by a private interest in France for assistance in establishing a testing and support group not only for Tay-Sachs disease but for the Allied Diseases as well. So it may be that the A's experience will not have to be repeated, and that the spirit of Sandrine and those who support her will benefit other similarly affected families.

Case No. 8: Feedback, from p. 3

Additionally, if a couple wishes to discuss this issue or any of the class material with us in greater detail we always offer to meet with them privately.

Since there are three people to meet with couples after class, it does not take long for everyone to be seen. These individual discussions allow us to have some brief personal contact with the couples and, most importantly, they allow us to address directly with these couples their probable response to an abnormal result.

The addition of an individual meeting with each couple after a group amniocentesis class might help to avoid some of the difficulties described in Case No. 8. I would be happy to discuss the model further with anyone who is interested.

Carla B. Golden, M.S.
Kaiser Permanente Medical Center
San Francisco, CA

Case No. 11: Ancient Culture to Modern Technology, from p. 3

prognosis of trisomy 21. YW immediately asked whose fault this was and what was the sex of the baby. We explained that the abnormality was an accident of nature that was no one's fault. Then we told them the fetus was male.

YW's husband remained withdrawn throughout the discussion. He looked at the wall and avoided eye contact with us or his wife. YW asked, "What should I do?" We reviewed the options and told the couple that we would support any decision they made. At that point YW became very angry at her husband. She said he had wanted her to terminate the pregnancy as soon as she knew about it. She seemed convinced that he had wished this on her, asking him repeatedly, "Now are you happy?" Our efforts to intervene were fruitless, as YW was no longer listening to us.

A D&E was scheduled at YW's request. Again, YW's husband was not present. When I arrived, I found a confused staff and a very upset patient. The interpreter told me that YW had changed her mind several times regarding the termination.

We cancelled the appointment and returned to my office. Our chief neonatologist, a Chinese physician, joined us. We spent two hours talking. YW revealed the following: •She did not wish to have a son who would require a lot of care and who would not be able to reproduce and carry on the family name. •If the child did, indeed, prove to be abnormal at birth, she hoped that he would not survive for long. •She was told by a faith healer that the baby's problem could be corrected by special herbs. •She could not understand how we could tell her what the baby would be like when we had not even seen the baby. •She thought that birth defects could go away, like a cold. •She thought the evil spirits brought her this misfortune and wondered if they would take the "curse" away if she pleased them. •She was not used to making such important decisions on her own. The doctor was supposed to know it all. We, of course, wanted her to make her own "informed decision." •She wanted to know why we couldn't guarantee her a normal child next time. •Her idea of mental retardation has to do with a few neighbors she had in her village in China, who were called "idiots" and had to be tied to trees. •She was told by an acquaintance that if the child was going to be abnormal, she could always "leave it some place." •She considered herself responsible for the abnormality, as she was the one carrying the unborn baby. If anything went wrong, it was because of something she did (or failed to do) or something she ate. •The child wasn't even born yet, how could he have any problems? •If the child was going to have problems that could not be cured, YW did not think that she could take care of him all the time. •She worried about what would happen to him after she died.

YW left this discussion saying that she would call us with her decision. We subsequently discovered that she later visited different health care providers, shopping for anyone who would tell her that there would be nothing wrong with the son for whom she has longed. Having been unable to find such reassurance, she terminated the pregnancy. It was clear to all of us that emotionally and physically, YW and her husband would not be able to cope with a handicapped child. It was also clear to me that by asking YW to comprehend the information we had given her, we were asking her to be a time voyager, moving her from a small village in ancient China centuries into the future to our own Western civilization with preventive medicine and informed consent. Had we left YW in her own times, none of this would have happened. She would have given birth to an "idiot" child and blamed it on the spirits.

Genetic Counseling Across the Lands: The Genetic Counsellor in Britain

by Joan Sneddon, MS, Medical College of St. Bartholomews Hospital, London

In Britain, non-medically qualified genetic counsellors are usually nurses, health visitors or social workers who have gained their knowledge and expertise on the job. This development may be due, in part, to the nature of the Health Service as well as to available resources.

Medical care, including clinical genetic services and genetic counselling, is provided by the National Health Service (NHS) and is primarily tax-funded. Patients choose a general practitioner (GP) who provides primary care and refers to specialist services when necessary. The GP as well as the specialist are paid by the NHS.

Current recommendations call for two Medical Genetics Specialists and two trained nurses in each Health Region (serving two million persons).[1] The demand for services in all health care areas has exceeded resources and, though the number of nurses working in this specialty has increased, these recommendations have not been fully implemented.

At present, there are about 50 nurses[2] working with genetic counselling services in the United Kingdom, many supported by short term funding obtained for specific projects and grants from special interest organizations. The role of these nurses has been described by a senior nurse specialist with a Regional Genetic Service[3] and is much the same as that of a genetic counsellor in the United States. There is no formal education for genetic counsellors although many of the nurses working in this capacity have degrees in genetics or biology. A Genetic Nurses and Social Workers Association exists and a working party is currently exploring the educational needs of nurses working in this specialty.

The Region in which I work in London (North East Thames) has a population of about 4 million. Genetic counseling services are provided by two medical specialists funded by the NHS and another University-funded senior lecturer. There is also an NHS funded senior doctor but the two regional genetics clinics have only a single secretary and no NHS funded genetics nurses.

It is my observation since arriving in this country in 1985 that resources are variable and tend to develop according to the research interests of those in a particular specialist area. It is possible to obtain short-term funding for research but difficult to gain established funding for clinical services.

My clinical responsibilities include assisting with the delivery of the AFP programme in hospitals near St. Bartholomew's Hospital in central London. Together with another nurse, I counsel patients with positive screening tests. Ours is the only District in the Region in which a specialist prenatal screening counsellor has the responsibility of providing counseling after a positive screening test. In the other Districts throughout the Region, it is done by an obstetrician, medically qualified geneticist, of a midwife as part of her general duties.

Although it is generally expected that genetic or prenatal counselling is done by a medical practitioner, the number of non-medically qualified genetic counsellors and genetic nurses in Britain has doubled since 1982. As screening and diagnosis become possible for more genetic conditions, the increased demand for clinical services will expand the role of the genetic counsellor and nurse specialist.

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1 Report of the Clinical Genetics Society Working Party on Regional Genetic Services. Supplement No 4, February 1982. The Eugenics Society, 69 Eccleston Square, London.

2 Guilbert, P. Letter. Nursing Times, 84(1):13,1988.

3 Fitzsimmons, B. Counselling for the future. Nursing Times, December 1985:22-24.

Book Bag

Family Studies in Genetic Disorders

by Anne J. Krush, M.S.S.A. and Kathleen A. Evans, A.I.M.S.W., Charles C. Thomas, Springfield, Illinois,1984, 241p., $28.50 hardback.

The authors intend this book to be "a handy reference and useful guide to family studies in medical genetics...of value to medical geneticists, nurses, public health professionals, and others who work with families with hereditary disease." In fact, the book does contain a great deal of information, much of which will be quite familiar to those already working in the field. I would anticipate that its utility for genetic counselors would be primarily as an overview to those beginning their training, or for those already in practice, as a review and useful resource for conducting family studies.

The authors begin with brief, but accurate, descriptions of genetic mechanisms—presumably aimed at health workers who have little background in this area. A more useful chapter on study design follows. Tables at the end of the chapter outline steps to be taken in designing family studies and are characteristic of the abundant "how to" examples in the book.

The chapter on pedigree construction is interesting primarily for its various illustrations and a brief discussion of sources of genealogic information.

Three chapters thoroughly discuss how to engage and support families during investigations and contain numerous anecdotal illustrations, but may seem obvious to the experienced genetic counselor. Similarly, the discussion of families' responses to genetic counseling is directed primarily at those with little clinical experience or familiarity with the genetic counseling literature. I was disappointed to see that the authors concentrated on mechanisms of contacting at risk relatives without really discussing ethical implications of this activity.

Unfortunately, the brief chapter on analysis and interpretation of findings is too superficial to be useful, although the reader is directed to references for further reading. A strength of the book lies in these references (few from the past five years), following every chapter. Appendices, comprising 70 of the book's pages, include a list of support organizations, a glossary with short but generally accurate definitions, references, and many examples of forms, letters and pamphlets.

An intriguing asset of the book is its reflection of the authors' experience as social workers in two different health care systems. For instance, the authors describe how conditions in the U.K. simplify data collection and patient follow-up. However, many of the techniques described are, by the authors' admission, not applicable to genetic studies in the U.S.

In summary, this book will be a helpful introduction for the allied health worker or physician with limited experience in genetic counseling.

Ann P. Walker, M.A.
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program to immunize all children under the age of five years.[1] While the program appears to be well underway in the major urban areas, the vast rural portions of Morocco continue to be difficult to reach. The success of the family planning project of information dissemination and services is also extremely difficult to assess. Intellectually, Morocco is well informed regarding problems resulting from over population, but continually must weigh this against its Islamic beliefs and practices.

Health care in general is available to Moroccans in urban areas, but is extremely inadequate in rural localities. The World Bank cites a figure of 18,000 population per physician, compared to the U.S. figure of 500 population per physician.[2] The vast majority of physicians have been trained in France, although the number of Moroccan-trained physicians is increasing since the medical school opened in the mid 70's. Nurses are trained in two-year programs as nursing assistants or registered nurses (the level equivalent of the licensed practical nurse in the U.S.).[3]

There are public hospitals provided by the directorate of public health where care is free. The family provides such items as sheets, blankets and food. Private clinics owned and operated by physicians are quite modern and the *polyclinique* system under the National Social Security Fund was established by royal decree in 1959.[1] These *polycliniques,* similar to Health Maintenance Organizations in the U.S., provide some of the best and most up to date health care in Morocco. Unfortunately, medical genetics, genetic counseling and birth defects/mental retardation evaluations are not available in Morocco.

I have been unable to obtain any statistics dealing with the incidence of birth defects or specific genetic disorders. Observation and discussions with friends are my major sources of information. A man who guards automobiles at a local restaurant has achondroplastic dwarfism (my observation and diagnosis); a young girl who lives in the mountains near Azilal has an unrepaired cleft lip and palate and a child in my daughter's preschool class has Down syndrome. While walking the streets of Casablanca, I have observed other individuals with Down syndrome and genetic disorder such as Treacher Collins syndrome, neurofibromatosis and limb malformations. Beyond these observations, it is difficult to assess numbers and almost impossible to assess intervention modalities.

For three years, I have worked part-time, first as the school nurse at the Casablanca American School and then as health consultant to the Health Unit at the American consulate in Casablanca. The major areas of health care that I have provided have dealt with well child care, immunizations, colds and flu and the "Casa Curse," a week-long bout of fever, chills, headache, nausea, vomiting and diarrhea. Occasionally I was able to provide some genetic counseling services, all in the area of prenatal diagnosis for maternal age.

As there are no American-trained physicians working in Morocco, the local medical community is utilized. Prenatal diagnosis information is rarely requested or offered as there are no laboratory capabilities in the area of cytogenetics or biochemical genetics. If a woman wishes amniocentesis or chorionic villus biopsy, she must travel to Europe or the U.S. Additionally, if prenatal abnormalities are diagnosed via ultrasound (which *is* available) or amniocentesis, termination can only be accomplished by hysterotomy if the pregnancy is beyond 12 weeks gestation. Although not encouraged, there are no religious or legal restrictions regarding termination of a genetically impaired fetus.

Of the six prenatal diagnosis counseling sessions that I have provided, it was interesting for me to note that two women had abnormal results on amniocentesis. One, age 38, travelled to the U.S. for amniocentesis and was found to be carrying a fetus with Trisomy 21. The family elected to terminate there. The other woman, age 42, had her amniocentesis in Paris. The results showed that the fetus had translocation Down syndrome [46, XY, t(21q 21q)]. She returned to Morocco and underwent a hysterotomy. Unfortunately, I was unable to convince the attending physician of the importance of confirming the diagnosis.

In addition to the prenatal diagnosis counseling, I have given a series of lectures to the biology students of the Casablanca and Rabat American Schools as well as to interested 5th and 6th graders. Consulate personnel have been interested enough to ask for a luncheon seminar on genetic counseling, but no counseling sessions have resulted. The American Women's Club considered the possibility of a presentation, but ultimately declined as they felt the topic might be "too sensitive."

For Morocco's lone genetic counselor, the experience has been somewhat frustrating professionally. Trying to understand recent advances in genetics via journal articles is at best, unsatisfying. The lack of colleague interchange and stimulation is sorely missed. However, even in light of these and a myriad of other frustrations—language deficit, being a female in an Islamic country, underutilization of a Ph.D. nurse and board certified genetic counselor—it has been a worthwhile experience. Culturally and socially, living in Morocco has opened doors to an entirely new world and has provided me with a better understanding of other cultures, as well as a better appreciation for my own.

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[1] Morocco: a country study. Foreign Area Studies. Nelson, H.D. Editor 4th Edition. The American University, Washington, D.C. 1978.

[2] The World Bank. World Development Report 1987, Oxford University Press. New York, June 1987.

[3] Country Profile - Morocco 1987-88, The Economist Publications Limited, 1987.

Perspectives in Genetic Counseling is published quarterly by the National Society of Genetic Counselors, Inc.
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Publication Date for Next Issue: June 30
Deadline: May 11

Prevention of Genetic Diseases in Cuba, from p. 1

individuals and 100 new cases per year.

A program for the prevention of genetic diseases and birth defects was launched in 1980 with the objectives of reducing the frequency of sickle cell disease, neural tube defects and chromosome anomalies. In addition, newborn screening for PKU and hypothyroidism was initiated. The sickle cell and neural tube prevention programs are built into routine prenatal care. At 16 weeks of gestation, a blood sample is drawn from all pregnant women and sent for MSAFP and hemoglobin electrophoresis. High and low MSAFPs are followed by counseling, fetal ultrasound and eventual amniocentesis.

In Havana City in 1986, 21,195 pregnancies (91.6% of the live births) were screened, 249 amniocenteses were performed and a total of 56 abnormal pregnancies were detected, of which 54 were terminated.

Carrier detection by hemoglobin electrophoresis in pregnant women is followed by testing the partner and providing genetic counseling. Prenatal diagnosis by DNA analysis on amniocentesis or CVS material for the S mutation is also available. During 1985-1986, 129 pregnancies at risk were detected in Havana City. Forty-nine underwent prenatal diagnosis and ten of 11 SS pregnancies were terminated.

The prenatal diagnosis program involving chromosome analysis is based upon risk factors determined by maternal age and low MSAFP levels.

The professionals in charge of all the clinical and counseling aspects of the program are medical geneticists, as there is an abundance of M.D.s. As the patient load increases, however, the need potential for master-level health professionals to perform administrative and counseling functions is becoming evident. The training of graduate nurses for those activities is being addressed.

The genetic counseling performed in Cuba is very similar to the U.S. As noted above, the coverage is free, universal, based on need and resources and is performed primarily by M.D. geneticists. Counseling is non-directive and geared to offer different options to individuals and couples who are able to make their informed reproductive decisions by themselves. The main problems encountered are related to the conditions of underdevelopment and poverty: inexperience of clinical geneticists, lack of effective communication systems for referrals, deficiencies in cytogenetic and biochemical genetics laboratories related to imported supplies and suboptimal public education in genetics.

Efforts are currently being made to overcome these limitations. It is likely that improvements will continue to occur as there is a public commitment to reduce human suffering by reducing the frequency of severe hereditary diseases and birth defects.

Letters to the Editor

First cousin marriages require genetic counseling in Maine

To the Editor:

On September 29, 1987, L.D. 1348 took effect in Maine, amending the prohibition of first cousin marriages. First cousins applying for a marriage license "...shall submit to the clerk...a certificate from a physician stating that the parties have received genetic counseling from the physician... ."

The passage of this bill lifted a ban on first cousin marriages that had been in effect for some time in Maine. Unfortunately, the bill does not require that the physician providing the counseling have any expertise in medical genetics. Since numerous reports cite the generally low level of genetics instruction available in most medical school curricula, we are somewhat concerned that the "counseling" that these couples receive may not be reflective of current knowledge concerning consanguineous marriages.

We hope to provide physicians in our state with up to date information on this subject via a statewide newsletter which is distributed quarterly to clinical offices, while we continue to seek the opportunity to change the language in the bill.

Yours truly,
Dale Lea, R.N.
Kathie Foss, R.N.
Foundation for Blood Research
Scarborough, ME

Sharing support expertise to reduce professional burn-out

To The Editor:

In response to Ms. Whipperman's and Ms. Perlstein's article "The Professional as a Person" (Vol. 9 No.4), I was reminded of some of the problems faced by social workers due to burnout and want to offer my services and center as a resource to any genetic counselor facing such problems.

Although I wasn't at the San Diego conference, the suggestions offered in the article seem to be right on target as a way of relieving stress associated with the genetic counseling function. Group functions are always helpful; however, there are some issues which seem so personal and unique to the counselor that individual counseling with a trusted friend or professional is particularly helpful. Because social workers also experience similar stress, they can be resource persons for genetic counselors.

In my private practice, I hope not only to attract individuals and couples needing psychosocial genetic counseling, but also to meet with professionals involved in their care.

I want to offer free access to my office during designated hours to genetic counselors in the area for support group meetings. Please feel free to write or call (202) 232-6409, 3000 Connecticut Ave. NW.,#439, Washington, D.C. 20008 if I can be of any assistance in setting up meetings or providing network services.

Sincerely,
Gloria W. McNally, Ph.D., L.C.S.W.
Consulting and Counseling Center
of Greater Washington, D.C.

Editorial Policy for 'Letters to the Editor'

Letters to the Editor are welcome and encouraged.

All letters must be signed and must include a professional affiliation as well as a daytime telephone number.

The author may request to have his/her name withheld.

The decision to publish letters will depend on the availability of space, the timeliness of the issue and the relevance to the readership as determined by the Editor.

Regional Conferences Planned

Region I: Plans are being made for a meeting in Region I this spring. Volunteers are needed to help with program planning and logistics. If you are interested in serving, please call me at (203)674-1465.

Andrea Gainey, M.S.
Region I Representative

Region II: May 19 - 20 has been set for the next Region II Educational Conference. The group will meet at Split Rock Resort and Conference Center in Lake Harmony, PA, in the Poconos. Members wishing to attend may contact me c/o Perinatal Center, Suite 115, 725 Irving Avenue, Syracuse, NY 13210; 315-473-4458.

Laura Child, M.S.
Region II Conference Committee

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Baltimore is Site of Conference

The March of Dimes Birth Defects Foundation and the Johns Hopkins Medical Institutions are co-sponsoring a clinical genetics conference, "Heritable Disorders of Connective Tissue and Skeletal Dysplasias," July 10-13 at the Baltimore Convention Center.

This annual conference will focus on the role of connective tissue in human development and maldevelopment, and will address cellular differentiation and development of the skeletal system, molecular pathology of collagen, elastin and other macromolecules both in heritable disorders of connective tissue and common rheumatologic disorders, as well as the diagnosis and management of skeletal dysplasia.

The conference has been approved for 21 AMA Category I credits and 2.1 continuing education units.

For more information, contact: Program Coordinator, Office of Continuing Education, The Johns Hopkins Medical Institutions, Turner 22, 720 Rutland Avenue, Baltimore, MD 21205; (301) 955-3168.

Carlita Kearney
Johns Hopkins Medical Institutions

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Early Death Topic of CT Meeting

"Dying Before Their Time: The Role of the Medical Humanities in Early Death from Genetic Diseases, Infectious Diseases and AIDS," has been scheduled for April 15 - 16. The conference is being held under the auspices of the University of Connecticut, Department of Medicine, Section of Medical Humanities.

The conference will focus on the impact of knowledge about early and impending death from various causes, such as Huntington's disease, leukemia and plague with an emphasis on AIDS.

The interdisciplinary faculty will stress the important role of counseling and support. All participants will be encouraged to share their experiences, insights and techniques in caring for these individuals.

Richard M. Ratzan, M.D.
U Conn Health Center

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UMDNJ Hosts 2nd Intercultural Counseling Workshop

The Division of Human Genetics, Department of Pediatrics of the University of Medicine and Dentistry of New Jersey, is sponsoring the Second Annual Intercultural Series, "Providing Genetic Counseling to the Vietnamese and Haitians."

These programs are designed to improve the participants' knowledge of the Vietnamese and Haitian cultures by exploring intercultural dynamics. The format will include case presentations and a panel discussion with ample time for attendee participation. A resource material exchange will also be available.

The Vietnamese cultural workshop will be held on Wednesday, March 30; the Haitian Cultural Workshop, on Wednesday, June 15.

For registration information contact Gwen James, Office of Continuing Education (201) 456- 4267.

Anne Timko-Scherer, M.S.
UMDNJ

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Trisomy 18/13 Meeting Scheduled

The Support Organization for Trisomy 18/13 will hold its second annual conference in Philadelphia, July 21 - 24. The program is planned for both professionals and families. Additional information and registration materials are available by writing to Ed and Pat O'Toole, 21 Ryers Avenue, Cheltenham, PA 19012.

Deborah Eunpu, M.S.
Advisor to SOT18/13

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Werdnig-Hoffmann Samples Needed

As part of an MDA-sponsored study to identify the genetic basis of Type I spinal muscular atrophy, (Werdnig-Hoffmann disease), peripheral blood samples from affected patients and their families are needed. Shipping costs will be defrayed.

For further information, please contact either: Thomas Carbone, M.D., Neurogenetics Laboratory, Massachusetts General Hospital, Boston, MA 02114; (617) 726-3826 *or* Barbara R. Pober, M.D., Division of Genetics, The Children's Hospital, 300 Longwood Avenue, Boston, MA 02115; (617) 735-6394

Barbara Pober, M.D.
The Children's Hospital, Boston, MA

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Two Important Reminders...

Our 1988/1989 Membership Directory is currently being prepared for publication. If you anticipate a change in your preferred or alternate mailing address, please submit the change, in writing, to our Executive Office *no later than Friday, April 22. Note to Students:* Please inform us of positions accepted as soon as the commitment is firm.

Luna Okada, MS
Membership Committee Chairperson

The cost of the 1986 Conference Proceedings will be raised from $20 to $29.95 on May 1. Please order your copy through the Executive Office.

Beth A. Fine
Liaison to Human Sciences Press

Computer Interface

Instructions for contributors regarding electronic or magnetic document transfer

Contributors wishing to submit a theme article, letter to the editor, case report, meeting announcement or other relevant articles are invited to communicate directly with Ed Kloza or Bea Leopold by modem or by computer disk.

Ed is working on an IBM/AT clone with a 30 megabyte hard disk and can accept 5 1/4"double sided, double density floppy disks in ASCII format. Bea is working on a Mac Plus with a 20 megabyte hard disk drive and can accept 3 1/2" double sided, double density 800K disks.

Disks will be returned, upon request.

Books

Charge Syndrome: A Booklet for Families
authors; Margaret Hefner, James Thelin, Sandra Davenport, Joyce Mitchell
publisher: Quota Club of Columbia, Missouri, 1987, 48 pp.
price: single copy free, $1.50 for additional copies
reviewed by: Connie Stewart, M.S. Children's Hospital Medical Center, Akron, OH

As stated in the title, this multi-authored pamphlet is geared toward families of children with CHARGE syndrome: Colobomas, Heart disease, Atresia choanae, Retarded growth and development and/or CNS anomalies, Genital hypoplasia, and Ear anomalies and/or deafness. Its purpose is to provide parents with general information about CHARGE, definitions of the medical terminology they are likely to encounter and resources for additional information.

The pamphlet can be easily read in one sitting. The first part of the pamphlet describes the cardinal features of the syndrome, their associated problems and methods of intervention and management. The unknown etiology of CHARGE syndrome is discussed along with an explanation of its recurrence risks and the current unavailability of prenatal diagnosis or prevention.

In the second section, a wide range of topics are covered, including the emotional impact on the family. The third section shifts from early physical problems to the development and education of a child with CHARGE syndrome. This section highlights issues that a family might face: growth problems, sexual maturation, intellectual ability, vision, hearing, speech and language, general health and education. A clear and concise glossary is included. The pamphlet closes with a list of national organization through which local CHARGE chapters might be accessed, as well as a list of publications written about children with general handicaps.

Overall, the pamphlet provides an honest view of the child with CHARGE syndrome. It does not try to paint a rosy picture or instill false hopes, but provides families with factual information without being overwhelming. The authors do not attempt to provide all the answers, but make it easier for parents to cope with the unknowns and to take an active role in their child's overall health care, which, the authors stress, should be an interdisciplinary approach.

The authors attempt to personalize the pamphlet by including photographs and short paragraphs written about individuals with CHARGE. These case stories stress both the similarities and differences between affected persons.

One drawback to an otherwise well-written pamphlet concerns a lack of cohesiveness in the format of the pamphlet. Sections headings are somewhat confusing; subtitles sometimes do not seem to relate to the main title of the sections. Additionally, the attempt at personalizing the pamphlet may have been more effective if, instead of presenting stories in separate sections, the authors gave an overall summation of the early years in the life of a child with CHARGE. Another point worth noting: because the authors refer to CHARGE as a syndrome, it may confuse readers who are familiar with CHARGE as an association.

These criticisms aside, this pamphlet is a valuable and scarce resource which brings together a vast amount of information dealing with CHARGE and presenting it in a clearly written and simplified way. Providing families with a pamphlet specifically on CHARGE syndrome succeeds in illustrating that they are not alone.

Audiovisuals

Diabetes and Pregnancy
produced by: Cindy Kemmerer, 1987
format: 1/2" VHS, (43:50 min.)
orders: Aultman Hospital, 2600 6th St. SW, Canton, OH
price: NA
audience: Diabetic women and their mates, ideally prior to conception; allied health professionals working with pregnant diabetic women
reviewed by: Kathie Tross, M.S., Children's Hospital Medical Center, Akron, OH

Diabetes and Pregnancy consists of three 15-minute sections which can be viewed sequentially or individually. Its producer has won a national award from the American Association of Diabetic Educators for this videotape and is currently writing an accompanying manual.

As an introduction to issues such as causes and management objectives, the first section "The Need to Know," is probably the least personal of the three sections. It is especially helpful, however, in its ability to explain the relationship between diabetic control and pregnancy outcome. It also discusses complications and birth defects, as well as management strategies. The mixture of interviews, graphics and narration holds viewer interest, although there are occasional awkward camera positionings. On-camera reinforcement of some analogies would be useful.

Section 2, "The Goal: Good Control," provides practical advice on maintaining control and is especially relevant for the insulin-dependent diabetic. The viewer is introduced to tests and preventive dietary measures by a pregnant diabetic woman. She shares her feelings about her difficulties maintaining control. The building of a human pyramid with cheerleaders who have names like 'Gary the Glucose Tester' and 'Don the Diet Follower' is a simple but efffective visual tool. The final section, "Labor and Delivery," is relevant to both insulin-dependent and gestational diabetics. The woman introduced in Section 2 is followed through her labor and delivery, complete with a tastefully-recorded C-section.

I would highly recommend that all three sections be viewed as a group. They would be a valuable addition to any genetics or obstetrics library.

Organizations

The National MPS Society is planning an intensive effort to locate families who do not know of their services. These services include a quarterly newsletter and national conferences.

The First International Congress on Mucopolysaccharidoses and Other Related Disorders will be held in May 1988 at the University of Minnesota. The society is particularly eager to reach families who might like to attend.

The group is requesting help from genetic counselors to locate the names of MPS families. Literature will be mailed to all the major hospital centers, in the hopes that genetic centers will be willing to mail the brochures to all appropriate families. MPS will follow-up promptly with anyone who makes contact.

MPS is also interested in reaching families with the following disorders: Hurler; Hurler-Scheie; Hunter; Sanfilippo-A,B,C, or D; Morquio-A or B; Maroteaux-Lamy; Sly; Sialicosis; I-Cell; Pseudo-Hurler Polystrophy; or ML IV.

For more information contact the National MPS Society, 17 Kraemer St, Hicksville, NY 11801; (516) 931-6338.

Classified • Classified • Classified

THE JOB CONNECTION, NSGC's streamlined job search service, combines our* Perspectives' *classified section with our jobs hotline. The classified listings printed in this issue represent the most recent additions to the service. Members interested in complete or regional information may receive a computerized printout by contacting the Executive Office.

PHOENIX, AZ: Progressive private practice has immediate opening for BC/BE Genetic Associate. Min 1 yr exp in prenatal diagnosis & reproductive genetics pref. Top-salaried position.

Responsibilities: Wide range of group & reproductive genetics, incl advanced maternal age & pre-conceptual counseling, amnio, CVS. Counseling opportunities with fetal surgical pts available, if desired. Team approach to MSAFP screening, high resolution ultrasound, diagnosis of congenital anomalies & PUBS available.

Send Resume: Bob Johnson, MD, United Genetics, 1300 N. 12th St., Suite 316, Phoenix, AZ 85006; 602-258-7582.

SAN JOSE, CA: Immediate opening for Masters-level, BC/BE Genetic Counselor in Permanente Medical Group. Exp pref. Computer literacy helpful.

Responsibilities: Wide range of duties, incl intake & family history; multidisciplinary hospital consulting, co-counseling & follow-up; specialty clinics; prenatal diagnosis & counseling; MSAFP; crisis intervention & counseling; teratogen counseling; community & inservice ed; research opportunities. CVS program under development.

Send Resume: John Mann, MD, Chief of Medical Genetics, c/o Kaiser Permanente, 260 International Circle, San Jose CA 95119; 408-972-3300.

SAN JOSE, CA: New, second position open for BC/BE Genetic Associate in private practice limited to prenatal diagnosis. State-approved MSAFP center. Salary competitive, based on exp.

Send Resume: John D. Stephens, MD, California Prenatal Diagnosis Institute, 1390 S. Winchester Boulevard, San Jose CA 95128; 408-866-6266.

STANFORD, CA: Immediate opening for Coordinator, Clinical Services in University Medical Center setting. Masters in GC, BC/BE req; exp in pediatric genetics pref.

Responsibilities: Evaluation, management & follow-up of clinic pts for wide variety of genetic disorders, incl. cranial facial anomalies, spina bifida; prenatal diagnosis; in-patient counseling; telephone triage.

Send Resume: Susan Schelley, MPH, Stanford University Medical Center, Genetics Center, A335A, Stanford CA 94305; 415-723-6858.

EDMONTON, ALBERTA, CANADA: Immediate Opening for Coordinator, Genetics Clinics. Must have background in genetics & public health care for this securely-funded senior position.

Responsibilities: Mix of supervision, administration & counseling in central and outreach clinics.

Send Resume: Dr. Peter Olley, University of Alberta, Department of Pediatrics, 2C367 Walter MacKenzie Center, Edmonton, Alberta T6G 2R7 CANADA; 403-432-4311.

FARMINGTON, CT: Masters-level, BC/BE Genetic Counselor wanted for research position at University of Connecticut Health Center in Department of Pediatrics, Division of Human Genetics.

Responsibilities: Investigating genetic linkage in hereditary osteoporosis, including ascertainment of families, coordination of home visits, collection of samples and data analysis.

Send Resume: Dr. Petros Tsipouras, Division of Human Genetics, University of Connecticut Health Center, Farmington, CT; 203-679-4691. EOE.

WILMINGTON and DOVER, DE: Two Public Health Masters-level genetic counselor positions available immediately. Competitive salary.

Responsibilities: Assisting clinical geneticist in satellite clinics; collecting histories; following-up with related health services; educating parents, community groups and professionals. Opportunity to become involved in hospital clinic rounds and specialty clinics.

Send Resume: Barbara Krausz, Genetic Services, Division of Public Health, P.O. Box 637, Dover, DE 19903; 302-736-4786. EOE/AA.

ATLANTA, GA: Immediate Opening for Masters-level BC/BE Genetics Associate in private laboratory setting. Salary mid $20s, depending on experience.

Responsibilities: CVS; prenatal diagnosis; cancer cytology; flow cytometry.

Send Resume: Charles Garrison, MD; Genetic and Laboratory Medicine, 5539 Glenridge Road, Atlanta GA; 30342; 404-256-4009.

HONOLULU, HI: Immediate Opening for BC/BE Genetic Counselor. MSAFP & computer exp pref.

Responsibilities: MSAFP screening; teratogen information; counseling for fetal testing & for pregnancies at risk.

Send Resume: Juliet Yuen, MS, Kapiolani Medical Center, 1319 Punahou Street, Honolulu HI 96826; 808-948-6834 or 6872.

BOSTON, MA: Newly-funded position for Genetic Associate in Sickle Cell Center is available immediately. BC/BE req. Salary range: $28,000 - $31,000.

Send Resume: Priscilla Blount, Boston Sickle Cell Center, 818 Harrison Avenue, FGH, 2nd Floor, Boston MA 02118; 617-424-5727.

BOSTON, MA: Immediate Opening for 3rd Genetic Counselor in Harvard Medical School-affiliated antenatal diagnosis center in 700-bed teaching hospital. Masters; BC/BE req.

Responsibilities: Pre-amnio counseling, CVS, PUBS, 12-week amnio, MSAFP. Research, lectures & individual project opportunities exist.

Send Resume: Janice Stryker, MS, Brigham & Women's Hospital, 333 Longwood Ave., 5th Floor, Room 520, Boston MA 02115; 617-732-7981.

BOSTON, MA: Position available immediately for BC/BE Genetic Associate at location 15 miles west of Boston.

Responsibilities: Patient counseling and case management in clinical oriented service, including amnio, MSAFP, cyto-genetic laboratory service. Competitive salary and benefits.

Send Resume: Ms. Christine Ford, Prenatal Diagnosis Center, Inc., P.O. Box 648, Lincoln, MA 01773.

BALTIMORE, MD: Immediate Opening for Masters-level Genetic Research Assistant. Five yrs clinical exp, computer literacy desired.

Responsibilities:Longitudinal study re outcome inborn errors of urea synthesis in referral, diagnosis & counseling center for related diseases; international in scope.

Send Resume: Saul Brusilow, MD, CMSC 301, The Johns Hopkins Hospital, Baltimore MD 21205; 301-955-5064.

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DETROIT, MI: Immediate Opening for Masters-level BC/BE Genetic Counselor in hospital setting. Exp. pref but not req.

Responsibilities: Varied duties incl Mendelian & chromosomal disorders; teratology; MSAFP; prenatal diagnosis. Research opportunities exist.

Send Resume: Lester Weiss, MD, Henry Ford Hospital, Dept. Medical Genetics, 2799 West Grand Blvd / CFP-4, Detroit MI 48202; 313-876-3116.

COLUMBIA, MO: Immediate Opening for Masters-level, BC/BE Genetic Counselor to join 3 medical geneticists, 1 PhD geneticist and 3 genetic counselors in University setting. No exp necessary.

Responsibilities: Case management of pts with metabolic disorders & coordination of existing MSAFP program.

Send Resume: Judith H. Miles, MD, PhD, Director, Medical Genetics, Department Child Health, University of Missouri at Columbia Hospital & Clinics, 1 Hospital Drive, Columbia, MO 65212; 314-882-6991. EOE.

EAST LANSING, MI: Position available immediately for BC/BE Genetic Counselor in University-based setting. New grads welcome to apply.

Responsibilities: Varied responsibilities, including pediatric and prenatal counseling; medical student and resident instruction.

Contact: Ann Swinford, MS, Michigan State University, Department of Pediatrics, B-240 Life Sciences, East Lansing, MI 48824; 517-353-2046. EOE/AA

ST. LOUIS, MO: Clinical Coordinator in nontraditional setting for high volume MSAFP testing program. BC/BE req. Position available 7/88.

Responsibilities: MSAFP clinical consultation, marketing & research.

Send Resume: Barbara Biesecker, MS, 11636 Administration Dr, St. Louis, MO 63145; 314-567-3905 x 555.

CHARLOTTE, NC: Second position available immediately for Masters-level Genetic Counselor in well-established, multi-disciplinary program based in 777-bed regional and tertiary care hospital..

Responsibilities: General & specialty genetic counseling; clinic coordination; prenatal diagnosis; MSAFP screening & counseling; teaching; clinical research.

Send Resume: James C. Parke, Jr., MD, Charlotte Memorial Hospital & Medical Center, Department of Genetics, P.O. Box 32861, Charlotte NC 28232-2861; 704-338-3156.

NEW HYDE PARK, NY: Immediate Opening for Part time (T/W eve+Thurs) Genetic Counselor with min 1 yr related exp in expanding outreach program. Travel in Queens req; BC/BE pref. Attractive compensation package.

Responsibilities: Diversified genetic counseling for prenatal & pediatric pts incl MSAFP screening, preamnio counseling, teratology, fetal anomalies. Counseling for positive results from NY State Newborn Screening Program.

Send Resume: Ms. Marie Murtha, Senior Employment Representative, Long Island Jewish Medical Center, 400 Lakeville Road, New Hyde Park, NY 11042; 718-470-8845. EOE.

ALBANY, NY: Immediate Opening for Masters-level, BC/BE Genetic Counselor in tertiary health care facility serving NE NY & parts of MA & VT.

Responsibilities: Collaborative program between Ob/Peds departments, incl counseling pts re: diagnosis, symptoms, prognosis, recurrence risks & follow-up; specialty clinics in Hemophilia, myelo clinics & other satellite clinics; professional & lay education.

Send Resume: Bernard Pollara, Ph.D., Dept of Pediatrics, Albany Medical Center, New Scotland Avenue, Albany NY 12208; 518-445-5120.

COLUMBUS, OH: Immediate Opening for Masters-level, BC/BE Genetic Counselor with min 2 yrs exp in Ohio State University-affiliated hospital setting.

Responsibilities: Diversified position incl counseling for pediatric, genetic, maternal-fetal medicine, OB/GYN, high risk pregnancy, and pre-existing genetic disorders. Public & professional education, coordination responsibilities for state MSAFP screening program opportunities exist.

Send Resume: Anne Marie Sommer, MD, Children's Hospital, Children's Drive, Columbus, OH 43205, ATTN: Beverly Page. EOE/AA.

PHILADELPHIA, PA: Masters level, BC/BE Genetic Counselor position open immediately in high-volume prenatal/perinatal hospital setting.

Responsibilities: PUBS, CVS, early amnio, intrauterine surgical cases, some teaching. Travel to satellite clinics req.

Send Resume: Lynn Godmilow, MSW, Pennsylvania Hospital, Department of OB/GYN, 8th and Spruce Streets, Philadelphia, PA 19107; 215-829-5633.

PROVIDENCE, RI: Masters-level, BC/BE Genetic Counselor position available 6/1/88 in Department of Maternal-Fetal Medicine. Some MSAFP testing & counseling exp pref.

Responsibilities: Varied clinical responsibilities: assist with statewide MSAFP program; preamnio counseling for advanced maternal age & other disorders; teratogen counseling; lecturing; participation in research & manuscript preparation.

Send Resume: Marshall W. Carpenter, MD, Women and Infants' Hospital, Department of Maternal & Fetal Medicine, 101 Dudley Street, Providence RI 02905, 401-274-1100.

SALT LAKE CITY, UT: Immediate Opening for Masters-level, BC/BE Genetic Counselor in major tertiary and perinatal referral center.

Responsibilities: Direct service in general genetics, prenatal diagnosis; specialty clinics.

Send Resume: Bonnie Baty, MS, Genetic Counselor, University of Utah Medical Center, 101 Annex, Salt Lake City, UT 84112; 801-581-8943.

CHARLOTTESVILLE, VA: BC/BE Genetic Counselor to join multi-disciplinary team consisting of 4 medical geneticists and 4 genetic counselors. Base salary range: $20 - 22,000.

Responsibilities: Varied duties incl prenatal & pediatric clinics; satellite clinics, education & research.

Send Resume: Pat Schnatterly, MS or Pat Allinson, MS, Division of Genetics, Box 386, Department of Pediatrics, University of Virginia Medical Center, Charlottesville, VA 22908; 804-924-2665.

CHEYENNE, WY: State-funded Genetics Counselor Program Manager position available immediately. Masters in GC, Nursing, SW, Public Health or related field; 1 yr exp in GC or BS with 3 yrs exp in GC. Related training considered.

Responsibilities: Provide statewide clinical genetics service & program management.

Send Resume: State Personnel, Emerson Building, Room 120, 2001 Capitol Ave, Cheyenne, WY 82002-0060; 307-777-7188. EOE.

While no good epidemiological data for mortality rates in Burkina are available, in a neighboring region where a vaccination project has been well accepted, the infant mortality rate is 142/1000 and for children aged one to four the mortality rate is 43/1000.[1]

In that area, the most frequent causes of death in children were associated with acute respiratory infections, malaria and chronic diarrhea with marasmus. In Burkina, measles and meningitis could be added to this list. As only a few children in the project area had been vaccinated, the infant/child mortality rates were at least as high as in the neighboring region. Although a vaccination program was brought to Burkina in 1987, not all families could be convinced that spending money to vaccinate children (about the price of one bowl of the favorite local brewed drink) was an appropriate use of their limited funds.

As a newcomer to the culture, I was interested to observe how those with physical differences or mental limitations were regarded by others in their community. Communication barriers in language and culture limited interactions with individuals or families. In this region, one of the most frequent and obvious physical differences was albinism. Individuals with albinism are easily integrated into the family and community although they are considered somewhat undesirable as marriage partners. There seems to be an empiric understanding by the population that the children of an albino may also have albinism.

I became familiar enough with one family to ask, through an interpreter, about their young daughter with Down syndrome. She was about five years old, the youngest child with several grown siblings. Some thought the child was "crazy," a term frequently used to characterize those who were different, while others thought that she had been affected by a *genie* or some other source of magic. The family politely but unconvincingly accepted my assurance that I had seen many children with the same problem and that it was the result of a mistake in the formation of the egg or sperm. The family was impressed that I "knew" that the mother was "old" without being told.

The only true genetic counseling interaction during this time was with a man who knew that he had hemoglobin SC disease. He was in his mid 20s, but was particularly interested in the heritability of the disease and quickly grasped the concepts of genes and random assortment. He was visibly relieved to learn that his children would not necessarily have this painful disease. During the time I was there, he experienced two major painful episodes. At the hospital he was given tablets for pain and sent home where he would sleep wrapped in a blanket on a floor mat. The hospital could only admit a small number of those who needed treatment.

In a country where medical supplies are limited, where there are few facilities for any kind of medical care, and the few trained medical personnel are charged with serving a vast population, the majority of individuals cannot receive even the most basic of medical care. Services for those with special needs do not exist. Genetic counseling, for the majority of people with whom I spoke, was complicated by the lack of education and the belief that evil spirits, magic and the "Will of God" are causative factors of difficult situations.

[1] Greenwood, B.M., et al., "Deaths in infancy and early childhood in a well-vaccinated, rural, West African population." Ann Trop Paediatr, 7(2):91-99, 1987.

Perspectives in Genetic Counseling
Vol. 10 No. 1 Spring 1988
a publication of the
National Society of Genetic Counselors, Inc.
Executive Office
233 Canterbury Drive
Wallingford, PA 19086