An investigation into the teaching of and curriculum development for inheritance and genetic diseases on the secondary school level.

AN INVESTIGATION INTO THE TEACHING OF AND CURRICULUM DEVELOPMENT FOR INHERITANCE AND GENETIC DISEASES ON THE SECONDARY SCHOOL LEVEL

A Dissertation Presented

by

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School of Education

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ABSTRACT

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Secondary school students are being inadequately prepared for an active understanding of genetic diseases. There is good evidence that students are being graduated out of high school, without even a basic knowledge of the more than two thousand genetic diseases. This work presents this evidence, as well as highlights some of the difficulties and challenges found in the teaching of genetics.

This project is aimed at ascertaining how much secondary school level, life science and biology teachers know about genetic diseases. Also, by concentrating on four specific genetic diseases

(Cystic Fibrosis; Tay-Sachs Disease; Sickle Cell Anemia; Thalassemia) that are representative of the racial and ethnic distribution in United states secondary schools, this study determines how much and to what degree, teachers are teaching about the subject.

Twenty-six life science and biology teachers from the Greater Boston Area, were randomly chosen from the junior and senior high school science teachers that volunteered to participate. All responses from the interview which contained twenty-six questions, were recorded and scored as to accuracy. A Reliability Test was conducted using the process of "test and retest", to determine the test's coefficient of stability. Data was analyzed by a VAX/VMS using the STATA statistical analysis program.

This research investigated four questions: (1.) Are biology and life science secondary school teachers teaching the basic principles of genetic diseases? (2.) Do biology and life science secondary school teachers know the basic principles of genetic diseases? (3.) Are biology and life science secondary school teachers teaching the characteristics and mechanisms of the four specific genetic

diseases--Cystic Fibrosis; Tay-Sachs Disease; Sickle Cell Anemia; Thalassemia? (4.) Do biology and life science secondary school teachers, know and understand the characteristics and mechanisms of the four specific genetic diseases?

Using the results of this study, a Genetic Disease Curriculum Strategy Format was developed. The purpose of this teaching manual is: (1.) to increase the level of science teachers' knowledge and understanding of genetic diseases; (2.) to enhance science teachers' instructional ability; (3.) to supplement existing biology and life science curriculum; (4.) to assist educators in writing new genetic diseases curriculum.

TABLE OF CONTENTS

Page

CHAPTER 1

INTRODUCTION

This presentation examines and validates the need for basic, teacher-understood, genetic diseases curriculum on the secondary school level. It also highlights the need for effective biology and general science curriculum that contain pertinent information on genetic diseases. The six objectives are as follows (with the last two objectives being the major portion of this work):

1. To show the importance of genetic diseases curriculum and instruction in the secondary school classroom.

2. To explain some of the challenges and difficulties that face teachers in the teaching of genetics in general.

3. To assess science educators' level of genetic diseases knowledge and understanding.

4. To ascertain which areas of genetic diseases instruction, are lacking in biology and life science classrooms.

5. To design a curriculum format based on the assessed needs, that will enable biology and life science teachers to produce their own genetic diseases curricula.

6. To structure a staff development manual for genetic diseases teacher education.

Twenty-six Greater Boston Area biology and life science high school teachers (representing nineteen communities) were randomly chosen and interviewed. This interview inquiry is not focused on whether or not teachers desire to teach about genetic diseases in their classrooms, but on whether teachers know what and how to teach about genetic diseases. The twenty-six teachers were asked about their perceptions of the effectiveness of their current general science and biology curricula.

From the results of this study (analysis of the interviews), a Genetic Diseases Curriculum Strategy Format addressing the status of current teacher knowledge, has been created by constructing and consolidating educational materials on genetic diseases. The Genetic Diseases Curriculum Strategy Format (G.D.C.S.F.) is a tool to assist teachers in the production of their own relevant genetic diseases curriculum.

The G.D.C.S.F. has been developed with five basic units:

Unit I--Introduction to the basic concepts of genetics and

genetic diseases.

Unit II--The historical record of genetic diseases.

Unit III--An examination of the nature of four specific genetic diseases (Tay-Sachs disease; Cystic Fibrosis; Sickle Cell Anemia; Thalassemia).

Unit IV--The human side (psychological and socio -economical) and the future implications of genetic disease research.

Unit V--Genetic disease resources for the classroom teacher and student.

Although each unit in the G.D.C.S.F. is progressive in information, none of the units (except for Unit I) are pre-requisites for the others. Unit I which contains basic DNA, cellular and chromosomal instruction, is necessary for the accurate understanding of the genetic process. The options to teach the units separately, to teach the units by integrating them into other biological materials or to teach all five units as a whole section, is given to each individual educator. The ordering of the classroom timing is also, left to the discretion of the teacher. The unit

presentations (3 weeks to 4 months) can be arranged to fit into an already existing science currriculum or can be expanded upon to formulate an entire semester course. Special instruction is given in the G.D.C.S.F., to adapt the units to both the junior and senior high school levels of the biology, life science or health curriculum.

The G.D.C.S.F. which is based on the findings of this teacher-needs interview study, contains teaching methodology that involves the organization and analysis of both pupil materials and strategies. This teaching methodology concerns the learner's perceptual organization, concept attainment, abstractions and insights. The outcome of thia approach is the understanding of the essential principles and ideas of genetic diseases.

With the methodology of the G.D.C.S.F., several comprehension strategies are employed in the assimilation of genetic diseases into the regular biology and science curriculum. The following basic patterns are used in the student approach of this content area: Enumeration--a listing of information like facts, events and ideas; Time/order--a sequencing of materials using time as a reference point; Comparison/contrast--likenesses and differences

among facts; Cause/effect relationships--showing how information comes into being (effect) because of other information (cause);Taxonomy--a classification of factual and conceptual definitions; Directional sequence pattern--the structuring of directives in a set of directives.

The criteria for the effectiveness of genetic diseases curriculum designed with the G.D.C.S.F., is evaluated by teacher-created examinations.

Need for the Study

Secondary school students are being inadequately prepared for an active understanding of genetic diseases. There is good evidence that students are being graduated out of high school, without even a basic knowledge of the more than two thousand genetic diseases.

Thomas Mertens ("You and Your Genetic Quotient--Part 2.") questioned 117 students at Ball State University in Indiana, as to what they remembered from high school, about human genetic diseases. The results were: 4.3 percent had learned about Cystic Fibrosis; 10 percent remembered studying phenylketonuria (PKU);

32.5 percent knew about Sickle Cell Anemia; 45.3 percent remembered hemophilia; 6 percent recalled studying about genetic counseling; 7 percent had learned about genetic screening; 9.4 percent remembered genetic engineering; 11.7 percent had learned of genetic disease prenatal diagnosis; 22.2 percent were taught the role of genetics in mental retardation; 17.1 percent were aware that DNA was a chemical substance of the cell. It is clear from these results that genetic disease information is not being effectively conveyed to our children.

Thomas Mertens also, combined 542 biology teachers with the 117 students, and questioned them on bioethical issues. 88.9 percent of them agreed with the statement that "Biology teachers have the responsibility of informing their students of genetic information that could affect future decisions."[1] An additional comment to this statement would be that the responsibility of disseminating genetic disease information, lies not only on the teacher, but also on those who write science curricula.

Since 80 percent of all high school students will take a course in biology before they graduate, genetic disease information

that we want to convey to the general public, should be taught as a part of this science curriculum. A planned program to raise our population's genetic quotient, would definitely provide our citizenry with a working knowledge of chromosomal aberrations and hereditary diseases.

An example of how we need a genetic diseases enlightened population, was cited by G.J. Stine who conducted a study of children born with Phenylketonuria (PKU). He found that 61 precent of the children's parents, did not know that PKU was an inherited disease. Also, 56 percent of the parents did not know that a special diet given to the child, would relieve the symptoms of the disease. This ignorance would not be, if pertinent genetic diseases information was being disseminated in our school systems.

A great deal of national attention has been directed toward the educating of our society, on sexually-transmitted diseases (examples: venereal diseases and Acquired Immuned Deficiency Syndrome). As sexually-transmitted diseases pose a threat to the nation's well being, this attention is justifiable. However, the lack of genetic knowledge is just as threatening, It cripples

comprehension, decision making and behavioral sensitivity.

Why should science teachers concentrate on the creation of new curricula? Curriculum and study guides accomplish many purposes in the educational process:

1. Guides heip to develop reading skills.
2. Guides compensate for individual differences and facilitate learning.
3. Guides foster activity when core questions are framed.
4. Guides focus on conceptualization.
5. Guides emphasize process as well as product.
6. Guides promote problem solving ability.
7. Guides encourage student independence.
8. Guides extend and reinforce the hierarchial order of information.
9. Guides help to develop language for conveying concepts.

Purpose of the Study

The purpose of this descriptive and comparative study, is to explore the importance and the lack of general genetics disease education on the secondary level. The purpose is also, to ascertain:

(1.) whether or not biology and life science secondary school teachers are teaching in their classrooms, about genetic diseases--in particular, Tay-Sachs Disease, Cystic Fibrosis, Sickle Cell Anemia and Thalassemia; (2.) whether or not biology and life science secondary school teachers understand the principles of genetic diseases--including the three basic categories of all genetic diseases; (3.) whether or not biology and life science secondary science teachers have access to curriculum based on genetic diseases.

From the results of this study, a Genetic Diseases Curriculum Strategy Format was developed. This Curriculum Strategy Format (GDCSF) enables teachers, as well as curriculum writers, to construct curriculum units that meet the educational needs of their student populations. It also assists teachers in their aquisition of basic genetic diseases knowledge. The resulting units are suitable for biology, health and life science classes, and are adaptable to both senior and junior high school environments.

Four basic genetic diseases--Tay-Sachs Disease, Cystic Fibrosis, Sickle Cell Anemia and Thalassemia--are emphasized in

this study. The selection of these genetic diseases, reflects the racial and ethnic distribution of students in the United States urban schools. Each of these diseases is represented predominately in a racial or ethnic group: Tay-Sachs Disease--Jews; Cystic Fibrosis--Caucasians; Sickle Cell Anemia--Blacks and Hispanics; Thalassemia (Alpha and Beta)--Arabic and Southeast Asians.

Another goal of this work, is to provide a means to empower teachers with the ability and confidence, to teach the constantly changing and challenging subject of heriability. By giving science and biology teachers opportunity to design their own genetic diseases curriculum with the G.D.C.S.F., they (the teachers) become more effectively involved with the subject matter and with their students.

In "Improving Schools From Within"., Roland Barth wrote about a group of teachers who were asked to prepare curriculum outlines for their coming school year. Even though some of the teachers' outlines reflected the curriculum of their teaching system, none of the guides were like that of others. Allowing teachers to write their own curricula, shifted the educator's

function from "passively compliant" to "actively creative". The empowerment of teachers enhances their classroom instruction control and their commitment to quality education.

> Mindless use of imposed curriculum leads to sandbox behavior and grit. Active contribution to and creation of curricula lead to honeybee behavior--and honey.[2]

Significance of the Study

By using an interview method and employing analysis techniques, the responses of a randomly selected sample of science and health teachers from a major urban area (The Greater Boston Area), will be surveyed and analyzed. The results from this study will determine to what degree new or updated genetic disease curriculum is needed. Also, information derived from this study, will be used to develop new methods of genetic disease curriculum construction.

The concern for more effective genetic disease education is significant to the educational world and to our society:

Ronald L. Abrell, in his paper "The School Will Be The Way", uses a quote from Doctor Albert Schweitzer, which exemplifies the need for our schools to educate young people to be helpers in the encouragement of life's development and expansion:

> The school will be the way! From the time they start school, young people must be imbued with the idea of reverence for all living things. Then we will be able to develop a spirit based on ethical responsibility and one that will stir many. Then we will be entitled to call ourselves a humanity of culture.(Schweitzer, 1959) [3]

All young people need to be challenged in their values formations and in their assessment of life in correlation with genetically-related diseases. Also, all students can learn the basic principles of genetics and genetic diseases, if the concepts are shown to be relevant to their life situations and are coherent with other parts of the biology, health or science course.

Due to the demands of the existing circumstances of life, all secondary school level students must be taught about genetically-related conditions. It is considered "that the majority of the population will have some involvement with a genetically caused condition in their lifetimes and that this is a sufficient argument for the inclusion of genetics in the biology course."[4] Accurate and effective teaching expertise and tools are necessary for today's science and health classes. This study reviews these aspects in respect to genetic diseases education.

Research Questions

The following questions were used by the researcher of this investigation, to assess the need for more teacher instruction and knowledge in the area of genetic diseases:

1. Are biology and life science secondary school teachers, teaching the genetic principles of genetic diseases?

2. Do biology and life science secondary school teachers, know and understand the genetic principles of genetic diseases?

3. Are biology and life science secondary school teachers, teaching the characteristics and mechanisms of the four specific genetic diseases--Cystic Fibrosis, Tay-Sachs Disease, Sickle Cell Anemia and Thalassemia?

4. Do biology and life science secondary school teachers, know and understand the characteristics and mechanisms of the four specific genetic diseases--Cystic Fibrosis, Tay-Sachs Disease, Sickle Cell Anemia and Thalassemia?

Limitations of the Study

This suggestive study which utilizes a genetic diseases questionnaire to obtain results for the construction of a curriculum

format, is not applicable to all educational settings or all science classrooms. The small study population is also, not intended to represent all United States life science and biology teachers. The intent, however, is for the production of usable genetic diseases classroom curricula.

CHAPTER 2

REVIEW OF LITERATURE

Introduction

The teaching of genetics on the secondary school level, is a unique challenge. It has been considered by some as a difficult task. This chapter examines the difficulties and challenges in the teaching of genetics in the high school classroom. It supports the main premise of this writing, that there is a need for teacher assistance in the teaching of genetics and genetic diseases, by way of subject materials, teachers' resources and staff development.

Although my main concern is for the teaching of genetically-related diseases, this review of literature will explain and expound upon some of the difficulties and challenges found in high school genetics education. Many secondary school science teachers do not have access to genetics or genetic diseases curriculum, and those that do, are having difficulties imparting this information. There are few references available, pertaining to this aspect of science education. However, those references that do exist, give a fertile basis for exploration.

The lack of effective genetic disease education, is directly related to the deficiency in genetic teaching programs, in general. The theme of this writing is not a reprimand of teachers for not teaching genetics or for not including genetics in established curriculum. Few educators would disagree with the statement that the study of genetics is necessary for the understanding of life. Also, very few high school programs do not include some genetics coverage in their life science courses. This is, however, to extol, to exhort and to reinforce. The extolling is to commend teachers who continually take on the task of teaching secondary school genetics. The exhortation is to strongly urge teachers to be aware of some of the obstacles that can hinder the successful teaching of high school genetics. Finally, the reinforcement is to re-aquaint teachers, with some of the reasons why genetics education should be valued in high school curriculum. It is also, to suggest ways of re-orienting and improving the methods in which genetics and genetic diseases are being taught--with particular emphasis towards curriculum development.

Even though genetics and genetic diseases can be taught and comprehended successfully, there are many difficulties and obstacles to overcome when teaching the subject. The following review of literature will highlight some of these challenges.

Literature Review

The following are issues that challenge the teaching of genetics on the secondary school level.

Student Comprehension of Basic Mendelian Genetics

> Teachers expect more than just successful performance on problems; they expect meaningful performance. Meaningful performance is a function of genetic knowledge, and is more than routinized use of problem-solving algorithms! A meaningful solution is one in which students can explain, in terms of genetics, why they carried out each step.[5]

High school educator James Stewart, conducted a study of 14 ninth grade biology students, to test their knowledge and problem-solving ability concerning three basic genetic problems using punnett squares. Examples of the problems, crossed:

1. monohybrid--genotype present--human parents with hard and soft bones;

2. monohybrid--genotype embedded within the phenotype description--beetles of red and white parents;

3. Dihybrid horses possessing long and short manes with palomino-colored horses.

An interesting point to teachers is that once the students shifted from the basic punnett square method to the algebraic method of probabilities and percentages, there was an accompanying decline in any reference to cellular division or functions. A student in this study, even developed a method which was a "composite of the punnett square and algebraic method."[6] Although it always lead to successful solutions, this method made it difficult for the student to relate what he was doing, to meiosis cell division.

This study shows that students tend to lose sight of the science that they are working with--which is the science of inheritance. James Stewart's underscored findings:

> With few exceptions students were able to provide acceptable definitions of most concepts used in instruction. However, they did have difficulty describing how concepts are related. The obvious suggestion for teachers, if their goal is to provide students with a coherent view of genetics, is to make their instruction more explicit in terms of concept inter-relationship.[7]

Teacher Preparation

In February,1988, students from six countries--United States, Korea,Spain, the United Kingdom, Ireland and four Canadian provinces--were tested in their math and science skills. Since the United States scored ninth in science, it seems that stiffer science course requirements and better course materials, are a must. Stronger courses require well-prepared teachers to teach them.

Some science teachers shy away from genetics and genetic diseases, because they, themselves, do not understand genetic concepts. Many were not taught in teacher preparation courses. Albert Shanker, President of the American Federation of Teachers, explains, "Teachers weren't required to take science (genetics) themselves; and if you don't know it, you can't teach it."[8]

According to Paula K. Haddow's work "Human Genetics Education in High School: A Pilot Program.", feels the way to accomplish the educating of teachers, is to develop statewide programs. Ms. Haddow is the director of educational services for The Foundation for Blood Research in Scarborough, Maine. Her model program consists of a two-day seminar that covers a variety of

topics: (1.) Basic human genetics; (2.) Screening for genetic disorders; (3.) Cytogenetics; (4.) Treatment and prevention of genetic disorders; (5.) Genetic counselling; (6.) A talk by a parent of a child who is afflicted with a genetic disorder.

Between October, 1978 and June, 1981, 46 percent of the science teachers in Maine, had attended Haddow's seminars. The consensus of participating teachers: "There is a need for more classroom materials that are relevant to students."[9]

Resources and Teaching Materials

Even when teachers have an educational background to teach genetics and genetic diseases, many are uncomfortable teaching this human-oriented science. This is another reason why good, accessible materials and resources are important. It is for this reason in 1978, that the National Clearinghouse of Human Genetic Diseases was formed in Washington, D.C. The N.C.H.G.D. was created by the Department of Health, Education and Welfare--Bureau of Community Health Services and Office for Maternal and Child Care. It collects, distributes and disseminates a wide variety of materials on human genetics.

Teachers do not always know what is available to them. However, by using the N.C.H.G.D.'s many offerings, teachers would be exposing their students to a wide range of materials. The more students are able to see the transference of the general principles of genetics to other areas of study and life, the more teachers will feel more comfortable teaching the subject.

Classroom Presentation and Subject Assessment

In traditional classes where genetics is being taught, facts are being doled out to students rapidly in the time period of one or two semesters and there is little analytical time allotted to students. Students are asked to mentally digest numerous descriptive materials without understanding the significance of the materials to life around them.

A. Radford and J.A. Bird-Stewart state in "Teaching Genetics in Schools":

> One of the major problems of teaching genetics is that it requires a certain amount of numeracy and analytical approach than most aspects of biology. Unfortunately, pupils with necessary numeracy and analytical ability are attracted in many cases toward the physical sciences and mathematics. Too many choosing biology are basically descriptive scientists only.[10]

Lesson plans must include more time for student observation work, but not at the price of mathematical know-how.

In regards to subject assessment, J.T. Pearson (a biology head at Crowley High School in England) and W.J. Hughes (science department head at the University of Liverpool) developed a method ("Designing an A-Level Genetics Course: II--Sequencing The Material and Developing a Strategy For Teaching and Assessment.") to determine whether or not the objectives to a science course have been attained. An assessment should take place during and after the genetics course.

Their method consists of two parts:

cognitive and affective.

The cognitive has practical procedures:

1. "recall of concepts"--keeping a checklist of covered concepts; comprehension and evaluation literature;

2. judgments on student's written summations or topic talks;

3. applications of mathematical techniques--checklisting how well students receive mathematical concepts.

The affective contains the following:

1. Awareness of the importance of genetics;

2. Awareness of the relationship between concepts;

3. Expression and formation of opinion.[11]

Field Trips

Students gain experience by going on genetically-related field trips. These trips can range from wildlife sanctuaries to research laboratories. The experience, if planned out as an integral part of the school work and course curriculum, can be edifying to the whole class.

The proposals for field trips, as Keith Gillett and William Scott point out, are under some pressure in the schools.

> It can be expensive in terms of supervision and travel and it can disrupt the rest of the curriculum if, as is common , whole days are required. With financial pressure, it is easy to envision field work as being a peripheral luxurious activity. It is a tribute to teachers that given the present restraints, there is still a great commitment to field trips.[12]

Field trips can be invaluable teaching tools and teachers must rally to keep them apart of the life science curriculum.

Textbooks and Mathematical Terms in Textbooks

There are many problems that can be found in textbooks and pre-published examinations. Although the format of these

educational tools are supposed to be geared to secondary school level thinking, they are not always.

> A major source of confusion, and one in both textbooks and examination questions, is the ambiguous and incorrect use of genetic terminology. If teachers are required to use these textbooks, and teach students to answer ambiguous and incorrect questions in examinations, it is quite understandable that much confusion is perpetuated.[13]

Textbooks for secondary school level biology and life science, have been in themselves a source of difficulty in the teaching of genetics and genetic diseases. Cho, Kahle and Nordland in "Genetics and High School Textbooks." identified the following areas as major sources of confusion and misconception:

A. Conceptual organization--particularly sequencing;

B. Conceptual relationships;

C. Use of terms;

D. Mathematical elements.[14]

At Wheelock College in Massachusetts, Jeff Winokur--a science specialist--, in his written report called "Changing How We Teach Science.", bluntly states,

> Try to stay away from textbooks. I know many people will disagree, but textbooks encourage memorization of vocabulary and facts.[15]

He goes on to say that some textbooks with kits of materials, can be valuable. However, for the most part, textbooks provide a reading, not a science learning activity.

Teachers should be aware of the incongruities of modern science textbooks. Biology and health educators are challenged to re-evaluate them. This issue also stresses the need for a strong curriculum foundation as the central focus for genetic classwork.

Student Pre-conceptions

Children come into the classroom with many pre-conceived ideas and notions about genetics and genetic diseases. Elizabeth Engels Clough and Colin Wood Robinson examine this in their 1985 work "Children's Understanding of Inheritance", in which they studied the responses of 84 secondary school students, to questions asked, prior to their taking biology classes. The concepts that they were testing, are: (1.) that acquired characteristics are not inherited; (2.) individuals in a species show considerable variations; (3.) some variations are inherited. The questions were related to mice, athletes and gardeners.

The following statements show some of the students' misconceptions:

> A. Yes, I think so....because....well if they (gardeners) get a lot of rough skin, I think it just carries on through the families.
> B. Mice with tails....because they (mice) had tails until they chopped them off....I think you might get a couple born without tails.
> C. ....genes are cells which are passed on from the mother to the baby when the baby is inside....it's when the baby is developing.[16]

Clough and Robinson conclude,

> We believe if students are to change in the way they think about inheritance in the direction of accepted scientific ideas, they need oportunities to explore their own ideas in a non-threatening atmosphere. The creation of this atmosphere and the devising of strategies for open exploration of ideas are real challenges for science teachers. It seems obvious that we must find ways of incorporating ideas from everyday experience into an essential component of any strategies developed.[17]

English educators J.T. Pearson and W.J. Hughes suggest that children as young as seven, have definite ideas about inherited characteristics. These teachers believe the way to deal with student ideas that are at variance with truthful concepts, is to build on ideas already held. One of the ways to combat student pre-conceived ideas, is by using newspaper and magazine articles during the time the genetics curriculum is being taught.

With these tools, new ideas can be molded in the minds of young people....as well as, incorporating an understanding that genetics has a larger scope than their classroom.

Curriculum Chronology

The sequencing of a genetics course, can be done in several effective ways. J.T. Pearson and W.J. Hughes point to four different methods. One is a chronological treatment where the simplest concepts are taught first and then harder concepts are introduced. The second is to arrange materials according to its structural logic. This is where one idea leads to another. The third is a problem-centered approach. The fourth is a spiral sequencing where new layers of meaning are added to concepts already learned.

The study of genetics and genetic diseases in an average secondary school life science class, usually gets squeezed in somewhere between cytology and protozoa, or between human sexuality and human anatomy. Time is a factor here. There are only so many hours of class time in a week. Priorities must be set. However, teaching genetics as a squeeze-in subject, is not doing the field of study justice. It gives the impression the concept of

DNA with its genetic coding distribution, is a tack-on. Nothing could be further from the truth.

Success Factors

Some students do experience learning difficulties with the topic of genetics. Bernard Longden, author of "Genetics--Are There Inherent Learning Difficulties?", examined this issue with recorded student and teacher interviews that were based on genetically-oriented tasks.

Longden asserts that there are factors that will determine and/or contribute to a successful learning process for students. Some teacher-influenced factors that influenced the learning process for students are:

A.Confidence and competence with genetics;

B. Perceived relevance of genetics within the curriculum;

C. Coherence and association of the concepts/principles with other parts of the biology course.[18]

Relevancy to the Environment

The strong correlation between genetics and the environment, must be firmly planted in biology and health students'

minds. It can not be excluded or played down as many curriculum guides do.

Jerry and Sandy Bornstein, a geneticist and journalist team, who are known for their outstanding books in genetics for high school students (What Is Genetics? and New Frontiers In Genetics.), make a special effort in their writings to stress that educational programs must include environmental hazards such as teratogens and mutagens. They reasoned "that these substances have unnaturally and dramatically increased the rate of mutations at the same time that advances in medical science have decreased the influence of natural selection."[19]

Summary

> There can be little doubt that the inclusion in the school curriculum of a basic treatment of genetics is relevant and desirable. The medical implications of genetics alone, with a significant number of diseases having a genetic basis, means that probably a majority of the population will have some involvement with a genetically caused condition at some time in their life.[20]

Effective curriculum with objectives addressing the issues that challenge the teaching of genetics and genetic diseases, will help students to comprehend some of the urgent, human problems

facing the modern world. Who better to create this curriculum, than teachers themselves. These are the individuals that relate and contend with this youthful population on a daily basis. The Genetic Diseases Curriculum Strategy Format (GDCSF), found in the following Chapter Five, is designed for subject mastery and teaching familiarity. Teachers using this tool, can adapt their classroom instruction according to the needs and academic levels of their students and still impart vital information.

CHAPTER 3

METHODOLOGY

Introduction

This chapter provides essential input into the structure of this writing's Genetic Diseases Curriculum Strategy Format--A Teaching Manual. The employed instrument (the questionnaire) will highlight the instructional strengths and weaknesses of science teachers (population) and existing science programs. The goal here is to describe the location of the sample, sample population, survey instrument, design, validity and procedures. This is a suggestive study which intent is for the production of genetic diseases curriculum.

Restatement of the Questions

The purpose of this study is to assess the need for more teacher knowledge in the area of genetic diseases instruction and the need for more genetic diseases curriculum.

Four research questions were developed to ascertain the current situation of genetically-related diseases instruction on the secondary school biology and life science classroom level.

1. Are biology and life science teachers teaching the genetic principles of inherited diseases?

2. Do biology and life science teachers know and understand the genetic principles of inherited diseases?

3. Are biology and life science teachers teaching the characteristics and mechanisms of Cystic Fibrosis, Tay-Sachs disease, Sickle Cell Anemia and Thalassemia?

4. Do biology and life science teachers know and understand the characteristics and mechanisms of the four specific genetic diseases: Cystic Fibrosis, Tay-Sachs disease, Sickle Cell Anemia and Thalassemia?

Subjects

The subjects of the research are secondary school biology and life science teachers in the Greater Boston Area of Massachusetts.

Twenty-six Greater Boston Area, high school biology and life science teachers were interviewed in order to ascertain their knowledge of genetic diseases--with specific emphasis on the four selected genetic diseases. This study's population was multi-

ethnic and racial: Caucasian (19), African-American (2), Hispanic (4) and Asian-American (1). Subjects were randomly selected from secondary school teachers participating in the summer Program in Biomedical Laboratory and Clinical Sciences at Boston University.

The subjects were selected according to the following criteria:

1. Current subject teaching assignment
2. Current grade level assignment
3. Current teacher certification

Instrument

This part was conducted by an in-person interview. This interview serves as the instrument of the study. The purpose of the instrument is to ascertain whether or not:

1. Biology and life science teachers have a general understanding of genetic diseases;
2. Biology and life science teachers know and understand the four specified genetic diseases;
3. Biology and life science teachers are teaching the four specified genetic diseases.

This section describes the interview instrument. It also includes the summary of the development of the interview.

The Development of the Interview

The questions for this interview instrument, are based on personal classroom experiences, discussions with school personnel, professional work with the March of Dimes Foundation and related literature.

The Description of the Interview

This interview instrument is constructed as a twenty-five item, semi-structured questionnaire. Each structured question (multiple choice) is followed by an open-ended question. The purpose of the open-ended questions is to clarify the structured questions.

To insure accuracy, the responses will were recorded mechanically using a tape recorder and transcribed onto data sheets.

The format to the interview is as following:

Questions 1 through 5--profile of the interviewee.

Questions 6 through 10--general genetics information.

Questions 11 through 13--refer to Cystic Fibrosis.

Questions 14 through 16--refer to Tay-Sachs disease.

Questions 17 through 19--refer to Sickle Cell Anemia.

Questions 20 through 22--refer to Thalassemia.

Questions 23 through 25--refer to curriculum guides.

The responses to the open ended questions, were scored on a three-point Likert-type scale. The responses to the structured questions were tabulated according to their correctness. The entire time of each in-person interview, were no longer than one and an one half hours.

A Reliability Test will be conducted using the process of "test-retest", to determine the test's coefficient of stability. This was obtained by administering the interview at two different times to the pilot study group.

Materials and Apparatus

For objectivity and efficiency a recording device (tape recorder) was used. The purpose of taping interviews is: (1.) to minimize the distraction of writing; (2.) to increase recall and data collection accuracy; (3.) to expedite the obtaining of information.

Design

This is a descriptive and comparative survey which is concerned with studying, analyzing and reporting about current secondary school genetic diseases teachings and genetic diseases curriculum. The interview approach is being used for this study since data supplied by the instrument proves to be sufficient for answering the questions.

In this interview section, a random sample of twenty-six science and health teachers were chosen from the entire number of those who volunteered to participate in the study. The prerequisites for volunteering are:

1. Teacher must be employed in the Greater Boston Area.

2. Teacher must have experience teaching biology and life science on the secondary level.

The subjects in the study group were selected also, by using a stratified random sample to gain a representative population.

Teacher responses were compared. Answers to both the subjective and the multiple choice interview questions, were judged for accuracy, by using the Massachusetts Department of

Public Health Genetics Guide (Units I,II and IV: October, 1986).

The concepts used and developed in the instrument were selected as objectives to attain the goal of this study. The variables which affect the outcome of this study are:

1. the number years of teaching experience;
2. the teacher's professional background (bi-professional or tri-professional);
3. the teacher's primary subject area;
4. the teacher's educational level;
5. junior high vs. senior high teaching experience.

Each of these variables was addressed by assessing the variable's existence (Interview questions 1 through 5), and by analyzing in percentages, the correlation of existing variables to subject responses.

Validity

The questionnaire instrument was developed from related genetic literature and materials. To assess its validity, it was reviewed by a panel of genetic instructors at the Bio-Technology Council Alliance, Cambridge, Massachusetts (David Form, leader

-1991). This panel determined the adequacy of the instrument from a technical point of view. The adequacy from a research stand point, was judged by the University of Massachusetts/Amherst School of Education doctoral committee (Amherst, Massachusetts).

A pilot interview was given to a small number of subjects, prior to the administration of this study's instrument. The reason for this was to make revisions as necessary. The instrument was developed to provide data from the respondents, which supports the purpose of this study.

Procedure

Collection of Data

A list of volunteer biology and life science teachers were reviewed. Using a stratified random sample technique, twenty-six teachers who teach in the Greater Boston Area, were selected. This group was composed of teachers from various cultural backgrounds.

When the validation of the instrument was finished, the interview was administered, in person, to the twenty-six biology and life science teachers. All interviews were conducted with

teachers from the Greater Boston Area and took place within the Program in Biomedical Laboratory and Clinical Sciences. The target months for the interviews, were July and August, 1991.

The subjects were interviewed using a tape recorder. The questions in the interview followed the order of the questionaire. Each participant was assigned a number for data collection and for confidentiality.

Data Analysis

After the interviews were completed, the responses were transcribed. The data obtained from the instrument, was processed at the Computer Center at Boston University. There a VAX/VMS, was employed to articulate the STATA statistical analysis program. STATA procedures include graphics, spread sheets, means calculations and standard deviation representations.

The responses of the subjects, were compared to existing laws. Any data collected outside of the established four research questions, that is relevant to the study, was presented in the results section of this dissertation.

Human Subjects Review

The use of human subjects in this study, followed the University of Massachusetts/Amherst written procedure of ethical standards established for research involving human subjects.

Summary

Genes are distinct sequences of chemical units of DNA, that blue print instruction for a specific structure, biochemical activity or inherited disorder. Research being done in the field of genetics, serves all the human community and has a great impact on the entire quality of life.

The present state of genetic disease education on the secondary school level, must be re-assessed. Modern high school students are not participating in an active understanding of genetic disease importance, structure or engineering. This situation is due to many difficulties and challenges that face the teachers and students.

There are optimistic solutions to these obstacles:

1. New teaching guides have to be developed;

2. New in-service workshops and seminars have to be presented;

3. New teaching presentation methods have to be formulated;

4. New textbooks have to be organized and written.

This work is aimed at ascertaining how much secondary school level, science and health teachers know and understand genetic diseases. Also, by concentrating on four specific genetic diseases, this study determines how much and to what degree, these teachers are teaching about the subject.

The resulting information of this chapter's work, was compiled and evaluated in the following chapter four, in order to create a the Genetic Diseases Curriculum Strategy Format of chapter five, for classroom use by science and biology teachers on the secondary school level. This educational tool aids the learning process, in the following ways:

A. To educate teachers to the inheritance principles and characteristics of genetic diseases;

B. To give both teacher and student an appreciation for the significance of genetic diseases;

C. To give students a knowledge of the mechanisms of inheritance;

D. To build student and teacher reasoning skills within the framework of genetic diseases education.

CHAPTER 4

RESULTS, ANALYSIS AND CONSTRUCTION

Introduction

This chapter presents the results and analysis of the administered Genetic Diseases Interview, which were used in assessing secondary school biology and life science teachers' knowledge and understanding of genetic diseases--with special reference to the four specific genetic diseases. These assessments were then used to formulate a basic structure of the Genetic Diseases Curriculum Strategy Format--A Teaching Manual.

Chapter four is divided into three sections:

Section One--Results of the Genetic Diseases Interview which contains each interview question followed by pertinent data concerning the teachers' responses.

Section Two--Correlation and Analysis of the Results which states and analyzes five major correlations found in the results of the Genetic Diseases Interview.

Section Three--The Construction of the Genetic Diseases Curriculum Strategy Format which utilizes the results and

correlations to determine what information is included or excluded in the Genetic Diseases Curriculum Strategy Format.

Results of the Genetic Diseases Interview

The following are the results of the teachers' responses recorded from the Genetic Diseases Interview Questions.

Questions 1 through 5 are interviewee questions.

Question 1: What is the name of the school and community you teach in?

Twenty-four different high schools from 19 Greater Boston Area communities, were represented. All of the high schools ,except one, have student bodies exceeding 500 pupils. Twelve schools were within a sixty-mile radius of Metropolitan Boston and fourteen schools were within a thirty-mile radius of Metropolitan Boston.

Question 2: How many years have you been teaching biology or life science?

The teachers' professional work years ranged from 2 to 34 years. Forty-six percent of the subjects had taught 26 or more

years. Thirty-one percent had teaching experience between 10 years to 19 years. Twenty-three percent had taught 2 to 9 years of high school science. The majority (seventy-seven percent) of this population could be considered "seasoned" educators with a decade or more of teaching classroom science.

Question 3: What is your highest level of education?

The educational background of the interviewees--highest level of attainment--were as follows: 8 percent held bachelors degrees; 84 percent held master's degrees; 8 percent held Doctor of Education degrees. Of the teachers with master's degrees (84 percent), 23 percent held a master's plus 60 credit hours, 9 percent held a master's plus 40 credit hours and 4 percent held a master's plus 30 credit hours.

Mostly all of the teachers (97 percent), expressed a desire to continue their education in order to improve their classroom presentations with up-dated information--this included the two teachers who held doctorate degrees.

Question 4: What is your teaching certification area?

All of the teachers, except three, were state certified in

biology. Of the three non-certified biology teachers, one was certified in life science and two were certified in general science. This indicates that the interview population was appropriately matched by random selection, for this type of interview questioning on biological aspects of genetic diseases.

Thirteen of the teachers were certified in one or more other fields of study. This included 8 teachers certified in chemistry. Some of the other certified areas were earth science, physical education, mathematics, social studies, english and the Italian language. The interview population had diverse interests.

Question 5: Do you have any other (besides science) profession or professional background?

Twenty of the twenty-six teachers (77 percent), answered "none" to this question. Of the six that did have other professional training: 2 were laboratory technicians; 2 were involved in real estate work; 1 was a nurse. The majority (98 percent) stated that they had no intentions to leave teaching for another profession.

Questions 6 and 7 are designed to ascertain the level of teacher knowledge in terms of the correlation between genetics

Question 6: What is the study of genetics?

Some examples of responses that reflected an understanding of the science of heredity:

"Pathways and probabilities of inheritance patterns."
"Understanding of the translation of DNA and all aspects of gene action."
"The study of chromosomal behavior."
"Transmission of biological information."
"Gene composition, interaction and protein control."
"Study of DNA and its sequence."

One teacher had a purely reseacher-mentality response: Genetics is "interrupting the DNA code and finding its application."

Since genetics is a study of the multitude of inherited traits, some of the responses seemed to have had negative slants:

"Disease Malfunctioning."
"Diseases carried and passed on the x and y chromosomes."
"The study of in-born errors."

These negative slant responses point out that some educators view the study of genetics as a study of "what can go wrong with organisms."

Question 7: What is the study of genetic diseases?

All of the teachers had comprehensive definitions:

"Understanding malfunctions of organ systems, which have genetic origins--whether chromosomal or molecular."
"Diseases transmitted their parental genetic tree."
"The study of genes (proteins) which cause problems

"Diseases transmitted to offspring from their parental genetic tree.'
"The study of genes (proteins) which cause problems (compared to the norm) in a population."
"When a deficiency occurs because of the inheritance of an imperfect allele."

Questions 8 through 10 are generalized genetics questions with question 10 being a historical inquiry.

Question 8: Which is not a dominant traits?

An inherited dominant trait is a trait that expresses itself more strongly than another (recessive). To this question, 62 percent responded correctly; 26 percent responded incorrectly; 12 percent did not know. Some of the teachers seemed to be perplexed in terms of the dominance or recessiveness of "specific" traits.

Question 9: Explain of dominant and recessive traits.

All the subjects gave appropriate definitions: (Note that an allele is each of two related factors that control a trait).

Dominant Traits:
"Needs only one allele to be expressed in offspring."
"Overpowers and wins out over the recessive."
"One allele will mask the other allele."

Recessive Traits:
"Traits not expressed."
"Hidden characteristics of an organism."
"Needs two alleles to be expressed in phenotype."

Referring back to question 8 and comparing it to question 9, there is a discrepancy in the responses. An explanation of this concern, is summed up in this way:

Although the teachers had an appropriate understanding of dominant and recessive traits, some (38 percent) did not have the applied knowledge to differentiate specific dominant and recessive traits. This is probably due to the fact that these teachers, when they were high school or college students, never memorized a basic generalized list of dominant and recessive traits.

Question 10: Who has been called "the Father of Genetics"?

There was 100 percent answer accuracy to this question. Gregor Mendel's contribution to the study of genetics, is also, well represented in the majority of high school biology textbooks.

Questions 11 through 22 pertain to specific genetic diseases:

Question 11: What is Cystic Fibrosis?

All those interviewed (except the 8 percent that did not know) answered this question by giving a single disease symptom:

"Accumulation of fluid in membrane lining of lungs."
"Excessive digestive secretions--often fatal."
"A debilitating condition of mucus thickened in the lungs."

There were some responses that did not appear to be accurately connected to Cystic Fibrosis:

"Muscular problems--co-ordination."
"Muscle tissue is replaced by fatty tissue."
"Disease affecting connective tissue."

Question 12: What are the symptoms of Cystic Fibrosis?

Only 8 percent of the teachers did not know that coughing due to mucous production, was a symptom of Cystic Fibrosis.

Question 13: Who are the majority of those affected with Cystic Fibrosis?

A total of 85 percent of the teachers knew that the majority of those who are affected with Cystic Fibrosis, are caucasians.

Question14: What Is Tay-Sachs Disease?:

Nineteen percent of the teachers did not know anything about Tay-Sachs Disease.

Some examples of responses:
"Recessive genetic disorder in which enzyme Hex A is lacking."
"Affects nervous system of young children--results in early death."
"Improper development of neuromuscular system."

Question 15: If both parents carry a trait for Tay-Sachs Disease, what is the chance that their fourth child will have the disease?

As to the question of the probability of Tay-Sachs Disease manifesting symptoms in a child, 35 percent of the teachers were incorrect.

Question 16: Who are the majority of those affected with Tay-Sachs Disease?

A small percentage (16 percent) of teachers were unaware that the majority of people affected with Tay-Sachs Disease, were of Jewish origin. Also, 8 percent of the interviewed population, considered Blacks to be at a high risk for Tay-Sachs Disease. Although these precentages are small, they indicate that there is still a lack of knowledge on this subject.

Question 17: What is Sickle Cell Anemia?

Excellent responses were recorded here with 92 percent accuracy. These responses were varied:

"Improper coding for hemoglobin in red blood cells."
"A spontaneous change in the shape of the red blood cells."
"Red blood cells take on the shape of the letter C: the cell's oxygen-carrying ability affected."

Question 18: What causes the pain in Sickle Cell Anemia?

The correct answer of blood vessel blockage was given by 85 percent of the teachers. Of the 15 percent incorrect responses, 12 percent of the participants were not sure of the physical pain associated with Sickle Cell Anemia. The others had no knowledge of the cause of pain associated with this genetic disease.

Question 19: Who are the majority of those affected with Sickle Cell Anemia?

All of the participants (100 percent) correctly answered that Sickle Cell Anemia primarily affects those of African or African-American ancestry.

Question 20: What is Thalassemia?

Of the respondents, 65 percent did not know what kind of disease Thalassemia is. Also, many stated that they had never heard of it.

Some of the correct responses:
"A lack of enzymes to properly breakdown protein."
"A blood disorder which is a recessively transmitted disorder."

Question 21: What are the physical needs associated with Thalassemia?

"Not Sure" was answered by 54 percent of the teachers, as to aspects of Thalassemia.

Question 22: Who are the majority of those with Thalassemia?

As to this question concerning the majority of people who suffer from Thalassemia, 92 percent of the educators, did not know that Southeastern Asians have the highest percentage of this genetic disease. Of these incorrect responses, 54 percent of the educators believed that Thalasemia affected, primarily, those of European origin.

Questions 23 through 25 are centered around classroom teaching and subject curriculum:

Question 23: Have you ever taught genetic diseases? Which ones?

A little over three-fourths (77 percent) of the teachers stated that they had taught genetic diseases. As to which diseases, the following is a percentage breakdown:

Sickle Cell Anemia--60 percent

Hemophilia--30 percent

Huntington's Disease--30 percent

Color Blindness--20 percent

Tay-Sachs Disease--20 percent

Cystic Fibrosis--15 percent

PKU--15 percent

Down's Syndrome--10 percent

Spina Bifida--10 percent

Diabetes--5 percent

Thalassemia--5 percent

Question 24: Does your science curriculum contain a unit on genetic diseases?

Forty-six percent of the teachers responded "no" to the question as to whether or not their biology or science curriculum had a genetics diseases unit.

Question 25: Would you like to learn more about genetic diseases? Which ones?

Ninety-two percent responded affirmatively. More information was requested for the following six specific diseases (which are listed from most to least number of requests):

Thalassemia; Sickle Cell Anemia; Tay-Sachs Disease; Cystic Fibrosis; PKU; Huntington's Disease.

Correlations and Analysis of the Results

To further understand the implications of the results of the genetic diseases questionaire, several important aspects were correlated using the IBM computer and the SAS (Statistical Analysis System) Graph and STATA Program. All correlations were taken from the participating teacher's genetic diseases questionaire responses.

Analysis of Teacher Profiles and Objective Scores

Each of the following correlations, is presented separately and is followed by an analytical discussion.

Correlation A. The Variables: Teachers' Overall Genetic Diseases Score on the Objective Questions By Whether or Not Their School Had a Genetic Diseases Curriculum. Out of the ten multiple-choice questions, an overall score of eight or more, was considered as a good understanding score and a score of seven or less, was considered as a fair to poor understanding score. Of the teachers (n=14) who had access to a genetic diseases curriculum guide, 64

per cent scored eight or more. Of those teachers (n=12) who did not have a genetic diseases curriculum, 58 per cent scored eight or more.

Teacher-capability in the area of genetic diseases information, is increased with the availability of a genetic diseases currriculum guide.

Correlation B. The Variables: The Presence of a Genetic Diseases Curriculum By The School System's Distance From The Metropolitan Area. Of those teachers (n=16) within thirty miles of the Metropolitan Area, 50 per cent had a genetic diseases curriculum.

Of the teachers (n=10) whose schools were 31 to 60 miles outside the Metropolitan Area, 60 per cent had a genetic diseases curriculum.

The probability of the presence of a genetic diseases curriculum, is slightly higher in schools located further from the Metropolitan Area. Greater attention and finances are sometimes devoted more extensively to specialized curriculum by outer metropolitan and suburban communities. Judging that teachers

seem to have a better teaching expertise when using a genetic diseases curriculum, this aspect stresses the need for school communities within metropolitan areas, to acquire or develop genetic diseases study guides.

Correlation C. The Variables: Overall Genetic Diseases Score By Years of Teaching. Teachers who scored eight or more (good understanding) on the objective questions were evaluated on their teaching experience. Science Teachers having taught one to ten years (n=6), scored 50 per cent; eleven to twenty years (n=13) scored 62 per cent; twenty one years or more (n=7) scored 71 per cent.

Although this aspect is not revolutionary, experience does count. The longer a teacher teaches science, the greater the chance that the teacher will acquire an understanding of various genetic diseases. It must be pointed out, however that the newer teacher to the science classroom needs assistance from a study guide. Curriculum or study guides are not only an outline for student acheivement, but also a resource for teacher-understanding.

Correlation D. The Variables: Overall Genetic Diseases Score By Distance of School from the Metropolitan Area. Of those teachers who scored eight or more, 63 per cent (n=16) taught within 30 miles or less of the the Metropolitan Area and 60 per cent (n=10) taught within 31 to 60 miles of the Metropolitan Area. There is no meaningful difference between these two groups. If a teacher has a good understanding of the subject area, it does not matter where that individual teaches.

Correlation E. The Variables: Overall Genetic Diseases Score By Highest Level of Teacher Education. The majority (n=22) of these randomly selected teachers held Master's Degrees. Of these teachers, 64 per cent scored 8 or more on the multiple-choice section. However,due to the small number of teachers with Bachelor's Degrees (n=2) and Doctorates (n=2), caution must be taken in reaching any conclusion here.

The Construction of the Genetic Diseases Curriculum Strategy Format

The analyzed results of the Genetic Diseases Questionaire, were used as a blueprint for the structure of the Genetic Diseases

The G.D.C.S.F. was written with a philosophy that contradicts many who participated in this study. The G.D.C.S.F. stresses that the study of genetics and genetic diseases, are not the studies of "what can go wrong with organisms", but rather they are the studies of "the many possibilities of organisms". Genetic diseases are apart of the many challenges that individuals face in life. When teaching classroom genetics, "Good" and "Bad" are judgments that should not be communicated to students.

Judging from the science teachers' scores, most of the teachers had a knowledgeable background information on basic genetics (DNA-Chromosomal). The G.D.C.S.F. Unit I (Basic Genetics Information) contains only supplementary material which can be used to complement student textbooks and current biology outlines.

Unit II (Genetic Disease History) does not cover Gregor Mendel and his work, since the teachers were knowledgeable of him and his accomplishments. However, the teachers were not able to recall historical background on genetic diseases. Therefore, the G.D.C.S.F. highlights important genetic diseases history in an easily

accessed, listed format which is provided within the classroom section called The Basic Genetic Diseases Historical Facts.

The teachers knew that certain genetic diseases occurred more frequently in certain racial and ethnic groups. With the exception of Thalassemia, the other genetic diseases were generally assigned correctly. However, when asked of the specifics of the four selected genetic diseases, the teachers could not respond in detail. Also, they rendered descriptions of the multi-faceted genetic diseases with single-symptom explanations. In order to expand the teachers' perceptions of genetic diseases, Unit III of the G.D.C.S.F. (The Nature of the Disease) explains many of the detailed aspects of these genetic diseases.

Since all the questioned teachers were interested in learning more about the contemporary issues (and sometimes, controversial) surrounding genetically-related disorders, Unit IV (Genetic Diseases and The Future) explores these topics.

Unit V (The Resources) of the G.D.C.S.F., lists numerous educational sources of literature and teaching materials. This section is in response to ninty-two percent of the biology and life

science teachers who felt that their textbooks were inadequate in supplying their students with information on genetic diseases.

Summary

Twenty-six biology and life science teachers from 24 different high schools in the Greater Boston Area, responded to 25 questions on the Genetic Diseases Questionaire. The purpose of the questionaire, was to assess: 1.the level of the teachers' knowledge of general genetics and inherited diseases; 2.the teachers' need for genetic diseases curriculum guides; 3.those topic areas that should be included in the foundation of the Genetic Diseases Curriculum Strategy Format.

All of the science teachers questioned recognized their responsibility to serve their students and had a desire to up-date their current genetic diseases teaching information. Many expressed a concern at not having a genetic diseases curriculum in their schools.

Teachers scored well on the objective questions (multiple-choice) involving general genetics, Cystic Fibrosis and Sickle Cell Anemia. However, the score accuracy decreased on Tay-Sachs

Disease and Thalassemia. Concerning the subjective questions (explanation), the teachers' responses were generally poor in quality in that the responses were incomplete. In that the majority of the subjects, described the specified genetic diseases with single symptom explanations. Few could integrate the principles of inheritance into their answers. The answers which were shallow and lacked depth, were not due to time restraints on the participants or a neglectful attitude by the teachers. The teachers were given unlimited response time to contemplate their answers and the teachers appeared to approach the task seriously. The problem was a teacher-knowledge deficiency.

Teaching experience, availability of a genetic diseases curriculum and school location were all shown to have an integral role in the effective teaching of genetic diseases. The more years of teaching experience in science that a teachers had, the higher that teacher's score was on the objective questions. Also, those participating teachers that had access in their schools, to a genetic diseases curriculum, scored higher on the multiple-choice questions. The presence of an already existing genetic diseases

curriculum, however, was more prevalent in schools farther in distance (thirty miles or more) from the Metropolitan Area.

The basic conclusions of this study, are: (1.)Genetic diseases curriculum provides a means for the teaching of accurate and correlated information on genetic diseases; (2.)Teachers need more genetic diseases information for the effective imparting of this topic to students; (3.) Even though experience increases teachers' genetic diseases classroom mastery, secondary school science teachers still, need to increase their own level of genetic diseases knowledge.

Finally, the analysis of the results of the Genetic Diseases Questionnaire, was used in the creation of the Genetic Diseases Curriculum Strategy Format. This structuring of the GDCSF was based on the findings of the scores and the expressed classroom needs of the teachers.

CHAPTER 5

GENETIC DISEASES CURRICULUM STRATEGY FORMAT--A TEACHING AND CURRICULUM CONSTRUCTION MANUAL

Introduction

The aim of this Genetic Diseases Curriculum Strategy Format is to increase scientific literacy and awareness of genetic diseases, in secondary school classrooms. The goal is also, for the promotion of building positive self-esteem and for the improvement of reflective, student decision-making skills. The G.D.C.S.F. is a teacher's manual containing a series of units that can be used to "customize" a genetic diseases program for both high school and junior high school science and biology classrooms. This curriculum-making format is designed to challenge and to stimulate students.

As a staff development instrument, the teaching focus of the G.D.C.S.F., is not solely student directed. It is a student-teacher reciprocal learning program in which both the teacher and the student are learning at the same time. The rationale of this

approach is that it is easier for students to add, summarize, clarify and predict given information, when the teacher is also, actively involved in the learning of the subject.

By combining past teaching experience, personal teaching style and student feedback with the G.D.C.S.F., teachers are encouraged to create their own genetic diseases curriculum. The flexible techniques of this format, are "teacher-friendly". The program design can be used to structure an entire genetic diseases semester course or it can be incorporated into an already existing life science, health or biology curriculum.

The timing for incorporating genetic diseases into a previously written curriculum, using the G.D.C.S.F., is variable and should be left to the discretion of the teacher. Generally, however, there are some intervals in science studies when the presentation of genetic diseases is most favorable to student learning. In biology courses, genetic diseases can be taught (1.) after cell function and structure is covered, (2.) while the Linnaeus Classification System of plants and animals is presented or (3.) during the segments on animal and human evolution, complexity and

specialization. For higher achievement level biology classes, genetic diseases can be integrated into biotechnology themes (an example: recombinant DNA) and laboratory exercises (an example: DNA electrophoresis). On this higher level, the G.D.C.S.F. can be used to give more detail on gene diversity. The middle or junior high school life science classes, can employ the G.D.C.S.F. during disease identification sections or after sections on human anatomy. In health courses, genetic diseases are best taught when various other diseases are being identified and examined.

In the Genetic Diseases Curriculum Strategy Format, the amount of material covered is reduced. Students become overwhelmed with large volumes of information. Retention is also, greatly reduced when young minds are saturated with facts. Most science textbooks are guilty of presenting students with a surplus of information. This genetic diseases format is designed to enable the teacher to streamline the amount of information given.

The elimination of rigid subject matter boundaries, is another aspect of this program. The objective is to integrate many facets of a student's world by showing connections. These connections

show the past, present and future of genetic diseases and how they effect individual lives. Student curiosity and creativity is promoted by letting students draw their own inferences from already known subject areas and genetic diseases situations. This emphasizes the conscious connection between the known and the unknown.

The G.D.C.S.F. is designed to help students to become critical and creative thinkers. This thinking process is composed of two aspects: (1.) Problem solving--the analyzing of puzzling situations in order to find solutions and (2.) Decision-making--the ability to select from many alternatives. The decision-making unit in the G.D.C.S.F. (Unit IV), by presenting in a series of questions, facilitates students in brainstorming their own opinions and knowledge of issues and concerns surrounding genetic diseases treatments and engineering. The questions ask students to address: (1.) What is the problem? (2.) Who has the problem? (3.) Where in the situation is the problem? (4.) Why is there a problem? (5.) Are there solutions to the problem?

Finally, the G.D.C.S.F. helps to strengthen the tie between what is factual in the mind of the learner and what is human reality, by making genetic diseases information accessible to both teachers and students, and by allowing a forum where invisible thinking skills can become tangible.

Unit One: The Basics

In this unit, a basic introduction of cytology is presented. It includes cell organelles, chromosomes and genetic engineering. The essential information should be presented to students prior to any formalized attempt to teach genetic diseases education. The teacher is requested here, to complete this unit before covering any of the other units. It is the only section of the Genetic Diseases Curriculum Strategy Format that is considered to be mandatory. Many of the newer secondary school biology textbooks contain most of this basic information. If this is true concerning an individual teacher's classroom textbook, then this unit's information can be used in conjunction with the textbook's material.

Teacher Strategies which is the second section of this unit, is designed to provide teachers with teaching methods and

suggestions that will enhance their teaching styles and increase their students' level of understanding. All strategies are adaptable according to the classroom environment and to available classroom equipment. Also in this section, Notes to the Teacher will add a personal touch of advice with teacher-skill ideas.

Section One: Basic Information

The Cell. Anton van Leeuwenhoek (1632-1723) with his simple lens microscope was one of the first to view a living cell--bacteria and protozoa.

Robert Hooke in 1665, was the first person to get a clear look at the outline of a cell. He viewed a small piece of cork. The grouping of what he saw, looked like monastary cell walls.....therefore, Hooke coined the term "cell".

In 1835, french scientist DuJardin became aware of the living substance inside the cell. This substance of life is called protoplasm. There are two kinds of cells: plant and animal. Both are made of this protoplasm.

Protoplasm is:

1. active and changing;

2. changes in chemical structure when the organism that it is a part of, dies;

3. substance that is like gelatin;

4. variable in color--depending on the type of cell;

5. 75% or more water;

6. 25% or less solids--one half of these are proteins.

Plant cells are the only cells that have a cell wall. The function of this wall is to keep everything in the cell. Also, cellulose, a starch-related substance, is found between the layers of the cell wall. Cellulose gives thickness and strength.

In animal cells, plasma membranes keep everything inside.

The size of the cell is measured in microns. There are 1,000 microns in a millimeter. Most cells are about 10 microns. Bacteria cells average about 1-3 microns.

The Cell Theory by Schleiden and Schwann:

1. The cell is the basic unit of structure for all living things.

2. All cells come from previously existing cells.

3. The cell is the basic unit of function for all living things.

The protoplasm of a cell is divided into organelles--each has a role in the functioning of the cell. The organelles are the nucleus, the nucleolus, endoplasmic reticulum, ribosomes, mitochondria, lysosomes, vacuoles, golgi apparatus, chromosomes, centrosomes, cell membrane and cytoplasm.

Mitosis is cell division. During this division the chromosomes become visible and replicate. The cell then, splits into two identical cells. This is accomplished in five stages--interphase; prophase; metaphase; anaphase and telophase. Meiosis which is cell division in gametes or sexual cells only, has an end result of the production of four cells from a single cell. Adding on to the stages of mitosis, there are four more stages of division in meiosis.

Chromosomes. The human genome--a term used for the complete composition of genetic information in an individual--is represented by twenty-three pairs of chromosomes in humans. A person's biochemical make-up is programmed by their genome. Some other genome or chromosome numbers for other living things are: Gypsy moth-62; Fruit fly-8; Frog-26; Corn-20; Pea-14.

Although Edward Strasburger, a German botanist, was the first to see human chromosomes during nuclear division, it was not until 1927 that H.J. Miller, an American scientist, discovered the correlation between overt mutations and chromosome irregularities.

Chromosomes are made of substances called DNA--deoxyribonucleic Acid. On the chromosome, there are alternating bands of light and dark genes. Studies, however, of DNA with x-ray diffraction show that the shape of the DNA molecule appears to be spiral. It was James Watson and Francis Crick who created a spiraled double-helix model of DNA with nucleotides. Each nucleotide is made up of three parts--a sugar, a phosphate and a nitrogen base. The nitrogen bases are adenine, quanine, cytosine and thymine (A,G,C and T). The bases are paired--adenine always with thymine and cytosine always with quanine.

A scientist that studies chromosomes is a cytogenetist. Cytogenetists photograph, cut-out, and arrange by pairing together, chromosomes in order to find out the karyote type of an individual. The 26 human chromosomes are classified in groupings. This is

"The Denver Classification System" which groups according to chromosome length and centomere position.

"The Denver Classification System":

Group A--Chromosomes 1;2;3.

Group B--Chromosomes 4;5.

Group C--Chromosomes 6-12 and x.

Group D--Chromosomes 13;14;15.

Group E--Chromosomes 16;17;18.

Group F--Chromosomes 19;20.

Group G--Chromosomes 21-22 and y.

A gene is that section of a chromosome that has a specific trait (inherited entity). It is also the smallest known unit of DNA. The specific inherited trait determined by a gene, is in the same location on each of the chromosomes in a pair. These corresponding gene pairs are called alleles. A close inspection of chromosomes, shows different horizontal bands on the chromosome surface, that vary in size.

When human sex cells (egg and sperm) which carry 23 chromosomes each, join for fertilization, they form the first body

cell with 46 chromosomes. The twenty-third pair of chromosomes determines the sex. Female body cells contain two x chromosomes. Male body cells contain one y and one x chromosomes. The results of combination: xy is female and xx is male.

The x chromosome is larger than the y chromosome. A gene that is found on the x chromosome and not on the y chromosome, is a sex-linked trait. A female is then, a carrier of a genetic disorder and the male has the outward manifestations of the genetic disorder. An example of this is Duchenne Muscular Dystrophy. Autosomal is a term used when the defective gene is not carried on the sex chromosomes (twenty-third pair). Therefore, both males and females can inherit the disease.

Section Two: Teacher Strategies

Cell Comprehension Strategies. The following are classroom teaching methods for cell comprehension:

A. Show students pictures of microscopes (simple and compounded) that are labeled. Have a class discussion of the function of each part and explain the history of microscopes. If possible allow students to view their own inner cheek cells

(stained with iodine) or view previously prepared animal and plant cells. Test students with an oral exam.

B. Let students examine small pieces of cork--texture; smell; color. Have a class discussion of the many uses of cork and of the reasons why Robert Hooke used cork.

C. Write topic on the board: "What makes something (plant or animal) alive?" Ask students to list 25 answers to this question. Remind students that their answers must pertain to both plant and animal life. Answers like "walking" and "talking" are incorrect. Go over the answers with students and cross out those answers that do not apply to all life. When someone comes up with the answer of "energy" or something similar, give that student a round of applause.

D. Present a discussion question to the class: If we know the ingredients of protoplasm, why is it that scientists can not make it in the laboratory? Answers: 1. Hard to study because protoplasm changes once it is removed from the cell; 2. A lack of knowledge of ingredient proportions; 3. The order in which to place ingredient proportions is not known.

E. Bring in a banana, orange, tangerine, ripe pear or plum. Let students examine the inner cellulose fibers that make wet mounts.

F. Let students view a millimeter ruler and have them visualize the size of a cell. Do simple math problems. Example: If I have 5 millimeters of skin, how many microns of skin cells do I have?

G. Assign each student an organelle. Research about the size, shape, location and function of that organelle, must be presented in a paper or in an oral report. Teams of 2 or 3 students can also work on this project.

H. Ask students which animal has a bigger sized cell: a rat or an elephant. The answer is found in quantity of cell and not in cell size.

Chromosome Comprehension Strategies. The following are classroom teaching methods for chromosome comprehension:

A. Give students small balls of modeling clay (perferably 2 colors) or home-made modeling dough (flour, water, salt and coloring). Have the class make 23 pairs of chromosomes, using the modeling dough.

B. Give students pre-made chromosomes (colored construction paper) with centromeres. The chromosomes should vary in shapes. Have students "pair" the 46 chromosomes according to exact shape and size.

C. Have students cut out mimeograph copies of DNA bases and then string the bases on wire or heavy thread.

D. To further illustrate DNA structure, use jellybeans or colored marshmallows and thin wire, to construct a double helix model.

E. For sex probability, use twenty marbles (20 light and 20 dark). The light ones will represent the y chromosomes and the dark ones will represent the x chromosomes. Place the marbles in a bag and shake. Take out two marbles at a time and record that combination. Each student in the class should have a chance to shake and pick the samples. Choose a class recorder. The class analyzes the results in terms of percentages.

F. When explaining the punnett square, use a felt board. Have cut-out pictures of flowers, plants and people. This allows students to visualize traits and to understand probabilities.

G. Ask each student to list 30 traits that they have inherited from parents and/or grandparents.

H. Using two identical, long beaded necklaces, place the stringed beads side-by-side. With masking tape and pen, ascribe a trait to a bead and to its corresponding trait (same bead on the other necklace).

Notes to the Teacher:

A favorite exercise of science teachers, is to have students do their own family trees. Please do not require students to do family tree pedigrees. It can cause many embarrassing moments in the classroom for the students. Also, it can create unpleasant situations at home for the parents and their relatives. If a child volunteers for this assignment and he or she has a large family, the family tree could be beneficial to the whole class. The key word here is "volunteer".

Another assignment would be to make up a song about their own family's pedigree or an imaginary family's pedigree. Another assignment would be to have the whole class create a family with an incredible amount of genetic disorders.

If you prefer a pre-structured format, "Chances' Choices" by Edward M. Kloza and Paula K. Haddow (GENESYStem, 1988), is an outstanding family tree curriculum. This curriculum which reads like a soap-opera or play, is constructed with believeable characters that all have interesting genotypes and phenotypes. Students become engrossed in this learning experience.

Section Three: Genetic Diseases Vocabulary

The following provides a listing of genetic diseases vocabulary:

adenine

alleles

amino acids

anti-codon

centromere

chromosomes

cytogenetist

cytosine

DNA

dominate trait

filial

gene

genetic engineering

genotype

guanine

heredity

incomplete dominance

phenotype

Punnett square

purebred

recessive trait

replication

RNA

sex-linked chromosomes

thymine

trait

Unit Two: Let's Talk About Genetic Diseases History

Introduction

This unit is designed to inspire the teacher and student, with valuable bits of historical information about past thought, research and accomplishment concerning genetic diseases. These basic facts of historical information, are given in a series form. This series is not chronological in order or in order of historical importance. However, the facts are presented in a way that is accessible to teachers. This unit will supplement the classroom presentations.

The Basic Genetic Diseases Historical Facts

A. In the British Museum of London, there are Babylonian tablets which were edited and translated. The findings were printed in the Cuneiform Text from Babylonian Text. These tablets show that even the inhabitants of Babylon were concerned about birth defects and human malformations. A whole list of genetic defects and disorders were given. Omens and divinations, however, were associated with such births.

B. Early societies in Europe, Near East, India,China, Japan, South America, Africa and North America (in particular, the

Eskimos), all held the ancient belief of maternal "impressions". This belief stated that the mental impressions of the pregnant mother (including shock, stress, and flight) influenced the production of birth defects in the unborn. Today, this idea is called the theory of "mental modification" and has not been totally ruled out by modern scientists.

C. The ancient Greeks ascribed to the "pangensis" theory which stated that health or malady was located in the semen. Anaxagoras (500-428 BC) viewed the female as the breeding ground and the male as a seed-producer. Semen was considered to be produced by the whole male body. Aristotle contributed that the female passed on form and structure, while the male passed on movement.

D. Leeuwenhoek (inventor of the early microscope), van Ham and Hartsoeker in 1677, actually viewed the sperm.

E. In 1814, a British publication called "A Treatise on the Supposed Hereditary Properties of Diseases.", expounded on familial diseases occurring more frequently in isolated environments by in-breeding.

F. Gregor Mendel's work was left unnoticed for 35 years after it was read to the National Science Association in Czechoslavia. In 1900, scientists Correns, Tschermak and de Vries re-investigated Mendel's work.

G. Waldeyer was the first to coin the name "chromosomes" after van Bereden in 1883, saw them equally distributed inside a nucleus. However, it was not until 1956, that 46 was established as the human chromosome number.

H. Sergei Rachmaninov, the composer and pianist, played his keyboard with hands that looked like octopus tentacles. His condition is believed to have been Marfan's Syndrome--a genetic disease characterized by cardiac weakness and very long limbs.

I. The description of diabetes was first found in an Egyptian papyrus. The Egyptians found that diabetes is an inability of the body, to use sugar properly. The pancreas does not produce the proper amount of insulin to digest the sugar and this could lead to kidney disease, heart disease and gangrene.

Based on historical findings, there is a strong genetic basis that diabetes may be inherited. However, scientists do believe that

diabetes is triggered by both genetic susceptibility and the environment.

Concerning Diabetes history, Douglas Coleman of the Jackson Laboratories in Bar Harbor, Maine, experimented with normal rats and genetically susceptible (diabetes) rats. He gave the identical amount and kind of food and water to both types of rat. When the week was over, he removed the food and left the water. The results were that the mice with the diabetic gene, lived 23 to 46 percent longer than the normal rats. The food that rats with the diabetic gene stored, seemed to have been used more efficiently. Coleman refers to this as the "thrifty trait." His work suggests that diabetes might be advantageous in environments where food is scarce (an example: Third world countries).

J. King George III of England who ruled 1760-1811, had severe fits of madness--paranoid schizophrenia. His rule was during the time of the American Revolution. Medical historians believed that he was actually suffering from Porphyria--an inherited enzyme imbalance. Porphyria is triggered by alcohol, barbituates and sleeping pills. Porphyria is also easy to detect because the sufferer

has wine-colored urine, and has symptoms of constipation, fever, fast pulse, hoarseness and weak limbs.

King George III nicknamed the "Mad King", was not a popular king due to his stubbornness in his dealings with the American colonies. In his 81 years of life, he fell victim to numerous "fits"--some of which he had to be strait jacketed. When tracing the lineage of the Royal Houses of England, the transmission of his inherited disease, is attributed to Mary, Queen of Scots. In 1811, King George III was replaced on the throne by the Prince of Wales, because of his disease.

K. The appearance of Porphyria, was and is greater than usual in the South African White population. National laws in South Africa have been passed that prohibit doctors from giving barbituates without first testing their patients for genetic difficulties.

L. In the past, there have been many kinds of genetic sensitivities to various drugs. Examples are the following: 1. Women with type A blood, who take oral contraception pills tend to double their blood clotting. 2. Succinylcholine--a muscle relaxant

used prior to surgery. In 1952, two patients in London, had prolonged paralysis. It is now known that susceptibilty to this drug, is a genetic variant. 3. Large doses of acetaminophen--an active ingredient in Tylenol--appears to trigger the formation of cataracts in some individuals.

M. In the seventeenth century, settlers (48 families) from Kent, England came to America, to avoid poverty and religious persecution. They settled on Martha's Vineyard--a small island of the coast of Massachusetts. There they inter-married with each other (first cousins with first cousins). By the end of the eighteenth century, almost 96 per cent of them were married to someone that was family related.

Nora Ellen Groce, a Harvard University anthropologist, researched the island's history. She found that the island's population had been greatly affected with the single gene disorder of deafness. The people who were farmers and fishermen, had adapted their lifestyles to include sign language. With contradiction to the past, the Vineyard's people, presently, do not have many cases of deafnes. This is due to the inclusion of other

heterogeneous populations with many genotypes. The island's population has changed considerably in the last two decades.

N. The Jewish Talmud warned Jews about a condition where extreme blood loss occurred after a baby boy's circumcision. They were told not to circumcize a baby whose two brothers had died.

In 1803, John Conrad Otto described the symptoms of an inherited disease called Hemophilia. In 1813, John Hay, a Reading, Massachusetts doctor, confirmed Otto's findings. Hemophilia is a condition where an individual bleeds freely without the benefit of an important, plasma-coagulate, protein factor. Through genetic engineering , Factors 8 and 9 (the important protein factors) are made available to those suffering with Hemophilia, as treatment.

Hemophilia has been determined to be a recessive defect found on the x chromomsome in the egg or sperm. Females are carriers of the disease and rarely suffer with it. The probability is however, that one out of two of her sons, will inherit hemophilia and one out of two of her daughters, will be a carrier. Males who have the defective x, will be hemophiliacs. For them, their daughters will all be carriers. Their sons however, will not have

any trace of the disease due to the fact that sons only receive the y chromosome from their fathers.

O. Queen Victoria of England had nine children. She was a carrier of Hemophilia. Two of her daughters (perhaps, three) were carriers, one son was a hemophiliac and two sons died early deaths (it is not officially known whether they had the disease). The generations of Queen Victoria: Her daughter, Princess Alice bore seven children--one son had Hemophilia and two daughters were carriers--; Her son, Prince Leopold had a normal son and a daughter who was a carrier; Her daughter, Princess Beatrice had one daughter who was a carrier and two sons who were hemophiliacs. Queen Victoria's son, King Edward VII did not have the disease and the Royal family of today, appears to be free of Hemophilia.

Unit Three: The Nature of the Genetic Diseases

Introduction

In this unit, four basic genetic diseases--Cystic Fibrosis, Tay-Sachs Disease, Sickle Cell Anemia and Thalassemia--will be explored and presented in four individual teaching modules. Each module presented is unique in its teaching approach. There is no implication here, that these four genetic diseases are the most important or prevalent of the genetically-caused disorders. The selection, however, is to reflect the racial and ethnic distribution of students in the United States urban public schools. Each of these diseases, is predominately represented in a racial or ethnic group: Cystic Fibrosis--Causasions; Tay-Sachs Disease--Jews; Sickle Cell Anemia--Blacks and Hispanics; Alpha and Beta Thalassemia--Arabic, Mediterranean and Southeast Asian peoples.

As a prerequisite, the three basic categories of all genetic diseases should be presented to the classroom prior to the presentation of the Four Specific Genetic Diseases Modules .

Classification of Genetic Diseases

At present, genetic disorders can be categorized into three subdivisions:

1. Single gene origin:

Each human being has a genetic format of approximately thirty thousand structural genes. Each gene controls the production of certain proteins that constitute the make-up of muscles, nerves, blood cells and all organ tissue. Normal metabolic functions, also come under the control of genes.

This disorder, caused by an error in the information stored by the genetic code at a single point, is the production of an erroneous enzyme or protein. This production may have multiple effects on the organism. It is the results of a mistake in a single piece of genetic information.

Sickle Cell Anemia is where a single amino acid substitution, causes the disease. This is due to an alteration in the DNA code. It is such a minor alteration and yet, this is what is responsible for all the clinical symptoms of Sickle Cell Anemia.

2. Chromosome Abnormality:

Chromosome disorders are caused here, by a situation where the normal bits of genetic information are either missing, extra-produced, or re-arranged. Usually, this has multiple effects upon the body. Frequently, the genetic piece of material can be identified and marked.

An example of chromosome abnormality, is found in 85 per cent of all patients with myelogenous leukemia. The appearence of these re-arranged chromosomes, shows that a portion of the number 22 chromosome has been transferred (lost or relocated) to the bottom of the number 9 chromosome. This re-arrangement has been named the Philadelphia Marker.

3. Multifactorial Inheritence:

The interaction of many minor genes contribute to a genetic trait. This is the opposite of a single gene's contributing action. The number of minor genes can be anywhere from 10 to 200. Some examples of traits controlled by this multitude of genes, are height, body structure, and finger prints. A high incidence of

genetic disease is observed , if there is an abnormal alteration in any of the interacting genes.

Although it is not known what the specific influence of the genes involved have, it is known that there are a number of congenital malformations that can be attributed to the malfactorial inheritance. Examples of these birth defects are cleft palate and cleft lip, spina bifida, and club foot.

The Four Specific Genetic Diseases Teaching Modules.

Notes to the Teacher:

Make a special effort not to refer to people with a genetic disease, with a descriptive noun. An example is making reference to a person as a "cystic, a "sickler", a "thalassemic", or a "Tay-Sacher". These terms which isolate and stereotype, have a negative effect on learning and compassion.

After each specific classroom presentation, reaffirm to students:

For human beings and other species, genes are our spice of life. Genes provide us with the ability to survive in a variety of environments. They also provide challenges for us to overcome.

The advantage is ours, if we are willing to learn and to adapt. Diversity in our genetic pool, is one way to ensure our existence as the human race.

Module One: Cystic Fibrosis. In the United States, 30,000 people have Cystic Fibrosis. In Canada, there is an estimated 3,000 persons with this disease. One in twenty Americans (primarily Causasions--1 in 1,600 births), is a Cystic Fibrosis gene carrier.

Cystic Fibrosis (CF) was first identified in 1938. The Cystic Fibrosis Foundation has funded research for over 35 years and has created a network of care centers throughout the country. In 1953, children born with CF, rarely reached elementary school before death occurred. Today, people live well beyond their twenty-first birthday. Tomorrow, research lends hope for the promise of an extended life.

Affecting the mucus secreting glands, CF inhibits breathing and increases mucus in the airways. The susceptibility to infections is increased. Digestion is hindered by the digestive enzyme process of the pancreas. Taking antibiotics and daily

enzymes is a must for CF patients. About 10 per cent of CF people, have diabetes. Although CF may damage the pancreas' ability to produce insulin, there is no proven evidence that connects diabetes mellitus and Cystic Fibrosis.

Cystic Fibrosis patients have abnormally high levels of sodium and chloride (salt) in their perspiration. This causes a problem only, when the weather is very hot, the patient has a high temperature, or the person is participating in intense physical activity. An excessive loss of salt can produce exhaustion, fatique, or stroke. Increased salt supplements may be added to the person's diet. Parents often give doctors a clue that their infant has CF, by reporting that the baby's skin tastes salty when kissed.

Symptoms of Cystic Fibrosis include coughing and wheezing, repeated lung infections, failure to grow or gain weight. The cough may be tenacious and cause frequent vomiting. Due to gas build-up caused by undigested foods, a distended abdomen is another symptom of CF.

In young children, Cystic Fibrosis is not always recognized and the symptoms can be attributed to other causes. However, one

symptom found in the first few days of an infant's life, is an obstruction of the intestines called meconium ileus. In the presence of this complication, surgery is usually indicated.

The Cystic Fibrosis gene is located on the chromosome pair number 7. The Cystic Fibrosis Foundation researchers are using markers as sign post to mark the location of the actual gene that causes the disease.

Diagnostic Testing:

At the present time, there is no blood test to identify carriers of the CF gene. There is a one in four chance of inheriting the disease, if both parents are carriers. An individual's DNA can be observed. The results can be relayed to other family members for further DNA testing for carrier status.

Prenatal Testing:

David J.H. Brook created a test to measure intestinal fluids in the aminiotic fluid. A certain enzyme (alkaline phosphatase) has been found to be decreased in the tri-semester of pregnancy--17 to 18 weeks. This condition indicates a fetus with CF. There is a 5 per cent error rate. For accuracy, however, this test can be done in

combination with the DNA testing. It is a more reliable genetic diseases testing tool for the detection of Cystic Fibrosis.

Notes to the Teacher:

1. Coughing is associated with contagiousness. Please stress, however, to students that people with Cystic Fibrosis (who cough frequently) are not spreading a CF germ. Explain that coughing is a way to loosen phlegm from the airways and remove it. Also, as a teacher who may have a student with CF, never give this individual a cough drop or suppressant.

2. In North America, medications (pills) are a vital part of life for the majority of people. Many school nurses report that CF students (as well as others with genetic diseases) either forget, hide, or throw away their medication. This child feels singled out as "different". Please be sensitive to this.

<u>Module Two: Tay-Sachs Disease and Allied Blood Diseases.</u>

Tay-Sachs Disease (TSD) is a fatal genetic disease which strikes young children and causes progressive destruction of the central nervous system. It is an inherited neurological disorder which affects the central nervous system. Usually, death occurs by age

five. Children with Tay-Sachs Disease appear until around six or seven months old. At that time rapid deterioration of the physical and mental skills, begins. There is no cure and life expectancy is only from three to five years old.

This disease is attributed to the presence of a vital enzymes called Hexosaminidase A (Hex A). There is a build-up of a lipid fatty substance--GM2 Ganglioside--in the nerve cells (especially in the brain cells). Although the disease is not clinically apparent until the child is several months old, the nerve destruction begins in the fetus. By the time the child is 4 or 5 years old, so much damage has been done that life can not be supported.

Dr. Warren Tay (1843-1927). a British ophthalmogist, first described the disease in 1881, as a cherry-red spot on the retina of the eye. Dr. Bernard Sachs (1858-1944), an American neurologist, first described the cellular changes. Sachs also, noted that the disease was familial in nature.

A newborn with TSD will develop and appear normal., until about the age of six months. The first detection signs can vary. First, there is a slowing down of development; second, peripheral

vision is lost; third, the child has an unusual startle-response. Convulsions and diminishing abilities of brain functions, are suffered by a child's first birthday. Nerve cells deteriorate relentlessly. With the loss of co-ordination, the child has a progressive inability to swallow and his pulmonary system becomes inefficient. By becoming blind, mentally retarded or paralyzed, the baby totally loses contact with the world.

Tay-Sachs Disease is an autosomal, recessive disorder. Either male or female can be a carrier of this trait. Both parents must be carriers in order to produce a child with the disease. A parent with a carrier status, is not affected physically in any way.

Tay-Sachs Disease can usually be found in a definite population of people. The chances are greatest, if the parents are of Eastern European Jewish (Ashkenazi) descent. 85 per cent of all children with TSD, are Jewish--that includes Sephardic Jews as well. In the United States, 1 in 25 Jews, is a TSD carrier.

A family does not always have a prior history for this disease to appear. The gene can be passed throughout many generations, before it is expressed. Before testing was available, the only way

to find out if you had this trait, was to have a baby with Tay-Sachs Disease.

Testing:

Prenatal diagnosis, pioneered in 1971, by Dr. Larry Schneck, is made by measuring the amount of hex-A in the amniotic fluid and cells of the pregnant woman. The fluid and cells are gotten by means of amniocentesis which is a procedure done around sixteen weeks after conception. During amniocentesis, a small amount of fluid from the uterus is withdrawn with a syringe through the mother's abdomen. If hex-A is present, the unborn child is TSD free. If hex-A is present with less amounts, the unborn child is a carrier. If there is no hex-A, the unborn child has Tay-Sachs Disease.

Men and non-pregnant women can be tested using basic blood serum. The National Tay-Sachs Disease Foundation and Allied Disease Association, encourages the blood testing of individuals prior to the event of pregnancy.

Concerning Allied Blood Diseases, there are other autosomal, recessive genetic disorders that are closely related to Tay-Sachs

Disease: Niemann-Pick Disease; Sandhoff Disease; Gaucher Disease; Krabbe Disease. All of these diseases present themselves in infancy or toddlerhood. With the exception of Gaucher Disease, the children usually die at or prior to their fifth birthday. Although all of the allied diseases affect Jewish people of either Central or Eastern European ancestry, Krabbe Disease is mostly common amoung Scandinavian people.

All of the allied diseases involve the breakdown and impairment of major body organs. There is either an overabundance of some substance (an example: Gaucher Disease--glucosyl ceramides is abnormally packed in body cells), or there is an overproduction of lipids (an example: Sandhoff Disease--fatty materials accumulate in a child's brain cells). Accurate testing is available for all of the allied diseases.

Counseling:

Genetic counseling is a vital part of any program concerned with genetic diseases. TSD counseling through hospitals and public health centers, is available to child bearing-age couples, who need to aquaint themselves with their reproductive options.

Notes to the Teacher:

Another prenatal, genetic disease testing procedure, is Chorionic Villus Sampling (CVS). The Benefit of this test is that the results are available within 48 hours and the test can be performed by the tenth week of pregnancy. In this test, a small piece of the placenta is suctioned away by means of a small plastic tube. The tube is inserted in the pregnancy sac via the womb. Although the safety factor of this procedure is still being judged, there appears to be no short-term effects on the developing fetus.

Module Three: Sickle Cell Anemia and Allied Blood Disorders.

Over 400 human hemoglobin variants of known structure have been reported. The most common clinically significant hemoglobin variants of the Sickle syndromes, can be classified as follows:

A. Sickle Cell trait (AS)

B. Sickle Cell Anemia (SS)

C. Sickle Beta Thalassemia (Double-heterozygous state)

In 1910, Herrick described a black student who had hemolytic anemia and elongated or sickled red blood cells. It is from this

beginning research that the various states associated with presence of hemoglobin S, are known today.

Sickle Cell trait is encountered in about 8 per cent of Black Americans. The red blood cells of these heterozygotes contain hemoglobin S and A. In parts of Africa where malaria is present, about 25 percent of the population have the Sickle Cell trait. These genes have persisted as a natural protection against falciparum malaria.

The life expectancy and death rate of individuals with Sickle Cell trait, resemble those individuals with normal hemoglobin (AA). Red blood cells with hemoglobin SA (Sickle Cell trait) develop sickling crises rarely and only when there is severe oxygen-deprivation.

Sickle Cell Anemia refers to a situation where an individual has homozygous hemoglobin S. This is attributed to a specific molecular lesion: the substitution of valine for glutamic acid at the sixth amino acid of the Beta chain of hemoglobin. When there is a lack of oxygen, red blood cells containing this hemoglobin S acquire an elongated or sickled shape. The red blood cells then,

become rigid and may obstruct capillary blood flow. Painful crises may result and appear anywhere in the body. The common sites are the abdomen, chest and joints. Chronic organ (kidneys, liver, brain and retina) damage is another is result.

Vocabulary:

Prior to beginning this lesson, have students look up the definitions to the following vocabulary words:

Anemia

Antibodies

Bone marrow

Centrifuge

Clotting

Electrophoresis

Hemoglobin

Plasma

Platelets

Red blood cells

Transfusion

White blood cells

Sickle Cell Anemia Pre and Post Test:

The J. Warsing Sickle Cell Fact and Fallacies Pre-and Post-Curriculum Questionnaire.

Answer true or false to the following questions:

1. There is a difference between Sickle Cell trait and Sickle Cell disease.
2. You can tell if you have Sickle Cell trait without a blood test.
3. Sickle Cell trait will cause you to be ill.
4. Sickle Cell trait can turn into Sickle Cell Anemia.
5. Healthy parents can have children with Sickle Cell Anemia.
6. We inherit the genes that cause Sickle Cell Anemia from both our parents.
7. Only individuals whose ancestors came from Africa can have Sickle Cell Anemia.
8. People who have Sickle Cell Anemia can give it to their friends.
9. A child with Sickle Cell Anemia can play and have fun like other children.
10. People with Sickle Cell Anemia have normal intelligence.

Student Demonstrations With Materials:

1. Using Play Dough modeling clay, have students make ten small, round models of red blood cells and ten same size models of sickled blood cells.

2. Give each student a 12 inch or longer straw (which represents a blood vessel) and a stop watch.

3. Have each student record the amount of time it takes for the round "blood cells" to travel to the end of the straw. Do the same for the sickled "blood cells".

4. Average out and compare classroom results. This is an excellent point for a discussion on blood cell clumping in Sickle Cell Anemia.

Classroom Information: There are over 400 different disorders of hemoglobin. Lack of oxygen and an increase in activity of the individual, causes these blood cells to become inflexible and sticky (potassium is depleted). Then, the blood cells do not flow smoothly through the blood vessel--but become crowded and jammed up. This created a painful "crises" condition in the one affected.

A Classroom Exercise: This is a scenario to be used in classroom disccussions called The Zimbabwe Saga.

Introduction:

This is a fictional saga of a West African family whose genotypes contain the recessive, autosomal trait of sickling red blood cell--also known as Sickle Cell Anemia. Throughout the scenario, Notes to the Teacher will be given.

Genotype Information: AA= non-carrier of Sickle Cell Anemia

AS= carrier of Sickle Cell Trait

SS= has Sickle Cell Anemia

Obe Zimbabwe was born circa 1700 A.D., in a large farming and hunting village in Ghana, West Africa. During his lifetime of 106 years, he obtained seven wives and was blessed with 38 children. Zimbabwe carried the Sickle Cell trait.

Note to the Teacher: Begin a discussion of the social and cultural history of Africa (especially religious and marital customs).

Zimbabwe's wife #1, Mari, had no sickling trait; wife #4, Tenicka, carried the Sickle Cell trait; wife #7, Oyana (Zimbabwe's last and favorite wife), had Sickle Cell Anemia.

Note to the Teacher: Have students do Punnett squares crossing each wife's geneotype (AA; AS; SS) with Zimbabwe's genotype (AS).

Mari had 8 children. Tenicka had 4 children. How many of these children carried the Sickle Cell trait? How many had SCA?

Note to the Teacher: The production of hemoglobin protein (Hemoglobin Alpha by chromosome #16 and Hemoglobin Beta by chromosome #11) is involved in Sickle Cell Anemia. HbA is the most common hemoglobin and HbS is the second. When an individual inherits both HbA and HbS, he/she carries the Sickle Cell trait.

Oyana who died 6 years after her last child, had five children who all carried the Sickle Cell trait. Why is this unusual? Why did Oyana die early?

Note to the Teacher: Discuss symptoms and treatment of Sickle Cell Anemia.

Around 1750 A.D., Falciparium malaria infested Zimbabwe's village. 22 of Zimbabwe's children survived. How many of Mari's, Tenicka's and Oyana's children survived? Did Zimbabwe survive?

Note to the Teacher: The Sickle Cell trait provided a specialized immunity against malaria.

Circa 1780, 18 out of Zimbabwe's 22 surviving children, were transported to America. 15 sons and daughters survived the journey.

Note to the Teacher: Lack of oxygen causes tension on red blood cells with HbS. This tension causes distortion of the cells. Discuss the conditions of travel on the transporting ships for Blacks to America.

Student Classroom or Homework Assignment:

Create a storyline and family tree (showing genotypes) of the descendants from four of Zimbabwe's American-born grandchildren. The grandchildren's genotypes: 2 with AA and 2 with SA. Options: Incorporate Italians, Greeks, Hispanics, Arabs or Southeast Asians into the family heritage. The End.

Although in the United States, Sickle Cell Anemia usually, occurs in Black and Hispanic people, it is also found in people and their descendants, from other countries--Greece, Italy, Israel, Sardinia, Turkey, Saudi Arabia and India. One in every 400 to 600 Blacks (1 in 10 Afro-Americans) Sickle Cell (SC) trait. One in 144 Black couples are in a situation where both partners carry the

SC trait. One in every 1,000 to 1,500 Hispanics inherit SCA.

Normally, red blood cells are round and the hemoglobin in the cells, is actively transporting oxygen to all parts of the body. However with Sickle Cell Anemia, the round, red blood cells are transformed into sickled shapes and the hemoglobin molecules are abnormal. In fact, the hemoglobin hardens and crystallizes. Sickling of the red blood cells causes thickening of the blood (increased viscosity). Most sickled cells are trapped in the spleen and destroyed. This leaves the person with a shortage of red blood cells. The normal life span of a red blood cell is 120 days. However, a sickled blood cell has half that life span.

The baffling question for scientists, is why do the sickled red blood cells stick to the endothelial cells of the blood vessels? It is known that loss of oxygen causes the cells to sickle and cram together in the blood vessels. This usually occurs in the bones or organs in the chest or abdomen. It is very painful and tissue damaging, when the organs are deprived of oxygen. A Sickle Cell "Crisis" is when lungs, brain and heart are negatively involved. Nausea, jaundice, recurrent fever, swollen joints and severe back

and chest pains, are experienced. Death or disability can lead from these episodes.

In infancy and childhood, most deaths under three years old, are due to Streptococcus pneumonia. This is due to the fact that the spleen is functioning improperly. Although it has its turbulence, adolescence is usually a calm time for those with SCA.

When treating his West Indian patients, James B. Herrick, a Chicago cardiologist, was the first (in 1910) to make a clinical description of SCA. He documented the presence of anemia and he took microphotos of the sickled red blood cells. Herrick, also, traced the disease to nine generations.

In the late 1940's, it was shown that a recessive gene was the transmitter of SCA. Both parents must have the SC trait, in order to produce a child with Sickle Cell Anemia. People with Sickle Cell trait, lead normal, productive lives and have no significant risk of hemoglobin problems.

Sickle Cell Anemia evolved thousands of years ago, in areas where malaria (carried by the Anopheles mosquito) was an ever-present danger. Studies done in Nigeria, show that infants who

carry the SC trait, have a protective, genetic resistance to malaria infections. Also, individuals with the trait, are protected against the most severe form of malaria--Plasmodium Falciparum. The oxygen level in the hemoglobin of the sickled cell, is reduced. Therefore, the parasite can not grow.

Presently, there is no cure. However, new therapies (Bone marrow transplants and a promising drug called Hydroxurea) reduce the severity and frequency of the Sickle Cell crises. The March of Dimes is a major supporter in this area.

Diagnostic Testing:

Hemoglobin Electrophoresis is a readily available blood test which can identify Sickle Cell Anemia or trait. This same test also gives information on other blood disorders.

Prenatal Testing:

An accurate prenatal test is also available. Johns Hopkins University School of Medicine has developed a testing process using DNA analysis which is 99 to 100 per cent accurate.

Concerning Allied Blood Disorders, G6PD (Glucose-6-Phosphate Dehydrogenase) Deficiency, another primarily Black and

Hispanic genetic blood disorder, occurs in red blood cells. G6PD is an enzyme in the blood cell that protects the hemoglobin from damaging environmental effects--such as medicine and chemicals. Although G6PD is related to Sickle Cell Anemia, it is not as severe.

When chemicals such as lead, carbon tetrachloride, benzene, ozone, cresol, chlorine, copper and naphthalene (in moth balls), are inhaled, the red blood cells of individuals with G6PD Deficiency, explode. Companies like DuPont have voluntary screening programs for sensitivity. At DuPont's Haskill Laboratory for Toxicology and Industrial Medicine, workers with G6PD trait, are offered placement in other areas where they will not be in contact with the hazardous chemicals.

Module Four: Alpha Thalassemia and Beta Thalassemia.

Thalssemia is a very common genetic blood disease. It has occurred in about 2,500 people in the United States. These people mostly are of Southeast Asian, Italian, Greek and Middle Eastern ancestry.

There are two forms of Thalassemia: Alpha and Beta. The type of Thalassemia depends on what part of the oxygen-carrying protein, is missing.

Alpha Thalassemia:

With Alpha Thalassemia, an individual (starting with the fetus) can not make any of the usual types of hemoglobin. Rapid destruction of red blood cells occurs. This anemia leads to many medical problems: gallstones; enlarged spleen; infections; leg ulcers. Life style is greatly hampered and life span is shortened.

The Alpha Thalassemia qualitative hemoglobin defect is located on the chromosome pair number 16. It is the result of one or two alpha globin deletions on each of the number 16 chromosomes. This genetic disease is common among Asian people from the following countries: Southern China; The Philippines; Malaysia; Thailand; Cambodia; Laos; Viet Nam: Burma; India; Sri Lanka; Indonesia.

Beta Thalassemia:

Known as Mediterranean Anemia, Beta Thalasemia was first described by Dr. Thomas Dooley in 1925. Beta Thalassemia or Cooley's Anemia, can range from mild to severe. In this disease, there is a mutation of chromosome pair number 11--the beta globin gene pair. Presently there are over 70 different kinds of mutations

in this beta chain. Beta Thalassemia Major, which is found primarily in the Mediterranean and South Asian population, is the most severe form. In this form, there is a drastic reduction of the production of red blood cells.

The symptoms of Beta Thalassemia, are usually first noticed in toddlers. The youngsters become listless, pale, fussy and prone to infections. The spleen, liver and heart become enlarged. Untreated patients risk death by infection or heart failure. Bones become brittle and distorted--especially the face.

Treatment for Beta Thalassemia is frequently blood transfusions. However, these chronic blood transfusions create the problem of major iron buid-up in the heart and other major organs. Death in the teens and early twenties, is due to this build-up. New drug programs, such as in chelation therapy, are helping to rid the body of excess iron. With this therapy, life span is of those with Beta Thalassemia, is lengthening.

Diagnostic Testing:

There is a DNA test (although very expensive) for both types of Thalassemia.

Prenatal Testing:

By using amniocentesis, it is easy to rule out those who do not have this genetic defect. In some cases, it is necessary to draw some of the fetus' blood with the aid of a fetoscope--an instrument used to view the developing baby.

Important Note to the Teacher:

Children who have a genetic disease, often have a very low self-esteem. Should you have a student with one of these diseases that causes chronic illness, make a point to emphasize the student's positive qualities. These students also, have self-limiting aspirations. Give them an opportunity to speak of themselves or their experiences in a classroom group discussion. The child with a genetic disease has strength. Look for them and allow him or her to use them.

As the teacher, commit yourself to being a positive force in the life of children with an inherited disease. Your attitude and approach will be of the utmost significance in maintaining a positive learning environment. It may take these children longer to complete the class assignments. However, please allow for this.

Basically, they are children trying to deal with a situation beyond their control. Be concerned, but do not feel sorry for the genetically handicapped. Convey to them that they, like all students, have unlimited possibilities for success.

Unit Four: The Human Side--Genetic Diseases Decision-Making

Introduction

With the applications of science and technology to reproduction, the analysis and study of the fetus is possible. These reproductive applications include artificial insemination, in vitro fertilization and surrogate motherhood (fetus transfer). Society, however, is presented with new questions of what standards of control should be implemented, when these procedures are performed. Ethical and metaphysical debates arises as to what "should' or "ought" to be done. Social and political policies are impacting the nature of parenting, social roles and heritage.

This unit is designed to challenge students in their thinking about genetic issues in their lives and the lives of those around them. Science, secondary school-level students have a perfect forum--the classroom setting--to discuss the new reproductive

methods and issues. Teachers must emphasize to students that there are no right or wrong answers in the exploration of their (the students') feelings, beliefs and philosophies.

Bio-technology

The human egg and sperm can be fresh, banked or frozen and can be joined together through artificial insemination, in vitro fertilization, intra-Fallopian transfer or surrogate embryo transfer. Presently the fetus can be viewed by radiographic and ultrasound procedures. Plus, amniocentesis can check fetal chromosomes and metabolic disorders.

There are three forms that future gene therapy will take:

1. Gene insertion:

An artificially prepared gene is placed into a cell.

2. Gene modification:

This is the alteration of already existing genes.

3. Gene surgery;

A defective gene is replaced by a normal gene.

In the future defective genes will be corrected. Hereditary disorders will be eradicated by treating or curing the defective

gene. Examples of this, is when a specific gene is missing due to faulty protein coding for the gene or when an altered or mutated gene is producing a defective protein. The goal of science is to advance DNA technology, to correct the problem.

The Inquiries

NOTE TO THE TEACHER: Due to the controversial nature of some of the ethical issues and the philosophies of the individual school administrations, parental consent may be required prior to classroom presentations.

The following is a list of questions (which can be modified for grade-level and content depth) for ethical analysis:

1. Who has reproductive freedom? Where should restrictions be placed?

2. Do the unborn child and its parents have equal rights?

3. Do children with genetic diseases and disorders have a right to be born?

4. Should parents whose families have histories of genetic diseases, be forced to have pre-natal testing?

5. Should it be routine for all people of child-bearing age to

be tested for genetic difficulties?

6. Does the ability to pay have a bearing on who has access to the reproductive techniques? Who will determine this? What is the responsibilities of medical insurance plans?

7. What are the rights of a frozen embryo?

8. In a divorce settlement, who gets custody of the frozen embryos? Are the embryos property?

9. Who should have access to confidential data in medical files?

10. Can an abortion be required of a mother that is carrying an unborn child with a genetic malformation?

11. Should the medical societies and associations, require doctors who perform human reproductive methods, to have special credentials?

12. How should The Church view the "naturalism" of these procedures?

13. Can abortion be justified for therapeutic purposes?

14. Is there any validity to the concept of "wrongful" birth? Is age, race or money a consideration in this matter?

15. Who is held responsible (the expectant mother, father, or both) for not seeking available fetal therapy when needed?

16. Is the view that women's personal choice of reproductive technologies, enhances their autonomy and empowerment, correct?

17. Does modern society value male children over female children?

18. Should modern biotechnology give parents the option to choose the sexes of their children?

19. What is your view of the establishing of Nobel Prize winners' sperm bank?

20. Who should control eugenics programs?

21. Are reproductive technologies considered a luxury item?

22. Should biotechnology companies who make reproductive products, be taxed?

23. Should biotechnology companies flood the market with genetic home diagnostic products?

24. Who should regulate the safety and validity of home diagnostic kits?

Bioethical Decision-Making Model

The following is a decision-making model based on a model created by Jon R. Hendrix at Ball State University. It is an uncomplicated model suitable for secondary school-level students' comprehension.

1. State the bioethical problem.

_____

_____

2. List the possible alternative actions or solutions to the problem (even if you do not agree with them). Five is the minimum.

SOLUTIONS	RANKING
a_____	_____
b_____	_____
c_____	_____
d_____	_____
e_____	_____
f_____	_____
g_____	_____

3. Rank these alternatives in order of preference.

4. Take the number one solution and list at least five values you hold that caused you to rank it this way.

5. Now take your number one solution and describe the consequences you think it might have.

6. How would this solution affect my.....

Money_____

Time_____

Personal Relationships_____

Family_____

Community_____

Psychological self_____

7. Are there any really "bad" consequences you could not live with?

8. List three reasons why others might not agree to your solution to the problem.

a_____

b_____

c_____

9. Restate your solution and place an "x" on the confidence scale.

My solution:_____

_____

CONFIDENCE SCALE:

I can live with my solution

I can not live with my solution

1_____2_____3_____4

Unit Five: Resources

Resources: Foundations and Agencies with Available Materials and Educational Services

A. The March of Dimes Birth Defect Foundation and the Department of Public Health--Massachusetts.

The March of Dimes along with the Massachusetts Department of Public Health--Genetics Program, has developed a general genetics curriculum called "Human Genetics: A Practical Teaching Guide."(October, 1986). This curriculum builds on basic cellular principles and becomes advanced with each section. The educator using this program, will have to simplify most of it before conveying the information to students in grades 7 through 12. The March of Dimes also, has a "Catalogue of Public Health Materials". Booklets, genetic series programs, informational sheets, educational kits, films and posters can be ordered for a small fee.

Although the March of Dimes is concerned about the screening of and counseling for specific genetic diseases, their main focus is toward the prevention of all birth defects. This prevention is

through the elimination of environmental factors. Smoking, drugs, the workplace, nutrition, alcohol drinking and pre-natal care are some of the environmental aspects addressed. Since 480,000 teenagers give birth each year (that is 1 in 8 U.S. births), The March of Dimes distributes an abundance of literature geared to this age group.

The Massachusetts Department of Health produces "The Genetic Resource" which is a free referral guide to genetic organizations and services. It is a bi-annual journal that also contains information on current research developments.

B. The National Tay-Sachs and Allied Diseases Association.

Newton,Massachusetts 02164

This association has booklets, posters and pamphlets available to teachers upon request. Although their main emphasis is on genetic screening, The National Tay-Sachs and Allied Diseases Association does provide an excellent pamphlet called "What Every Family Should Know." that explains the genetic disease-related crises.

C. The Cystic Fibrosis Foundation.

United States and Canada.

The Cystic Fibrosis Foundation provides numerous booklets and informational guides (including their own national newspaper called "The Commitment"). Most of their publications are directed towards the individuals and families who are directly affected by the disease.

The CF Foundation considers teachers as "caregivers". Both the United States and the Canadian CF Foundation distribute a publication called "A Teacher's Guide to Cystic Fibrosis." Many of the question a teacher might have concerning CF, are answered here. Also available is a handbook entitled "Talking with Children with a Life-Threatening Illness". This particular work prepares teachers to instruct students on specific issues relating to CF and the school environment.

D. The Boston Sickle Cell Center.

Boston, Massachusetts.

The Boston Sickle Cell Center, founded in 1972, is a comprehensive program that offers free educational, counseling

and testing services. It is the central organization (located in the Boston City Hospital) of many of the leading Sickle Cell Anemia centers throughout the USA. For people utilizing their services, the testing and educational programs are at no cost.

All educational materials give the complexity of Sickle Cell Anemia. The following publications are available through the Boston Sickle Cell Center:

1. "Learning About Hemoglobin--AC, CC, SC. This is plentiful in maps, statistics and diagrams.

2. "Sickle Cell Trait and Sickle Cell Anemia." This is also available in Spanish.

3. "Your Child and Sickle Cell Anemia." This is particularly good for teachers' understanding.

4. "Tell Me About G6PD." This concerns the absence of an enzyme that protects blood cells from strong oxygen compounds.

5. "What Shall We Do?" This addresses decision-making.

Resources: Additional Sources of Educational Materials

This is a listing of some of the sources where teachers can obtain supplemental genetics and genetic disease information and classroom aids.

A. "Catalogue of Public Health Education Materials."

March of Dimes Birth Defects Foundation

White Plains, New York 10605

This contains films; video tapes; publications; educational kits; posters; exhibits.

B. "The Genetic Resource."

Massachusetts Genetics Program

Division of Family Health Services

Massachusetts Department of Health

Boston, Massachusetts 02111

This is a bi-annual publication with current information on new research in genetics. Examples: 1. "Pre-natal Diagnosis of Cystic Fibrosis."; 2. "Genetic Linkage Test For Huntington's Disease.": 3. "DNA Diagnostic Testing: Laboratory Service Issues."

C. The Genetics Screening Study Group

Harvard University Medical School

Longwood Avenue

Boston, Massachusetts

This group is responsible for a collection of articles that are prepared to provide scientific and medical background on genes and human behavior. Examples: 1. "Social and Political Uses of Genetics in the U.S.: Past and Present."; 2. "Is Science Creating a Biological Underclass?"; 3. "Hide, Rosie, Here Comes the Fetal Police."

D. IBA Biotechnology Information Center

Washington, D.C.

This contains publications; slide shows; documentaries and videos.

E. National Association for Sickle Cell Disease, Inc.

Los Angeles, California 90010

This contains home study kits; learning games; booklets.

F. Northeastern University Library

Huntington Avenue

Boston, Massachusetts

The materials contained here are books and articles from journals, newspapers and magazines that have detailed information on various aspects of Sickle Cell Anemia.

G. "Preview"

Cambridge Development Laboratory, Inc.

214 Third Avenue

Waltham, Massachusetts 02154

This contains science computer software for junior and senior high school students. The genetic disks cover DNA; RNA; protein synthesis; cloning in plasmids; recombinant DNA; human genetic diseases.

H. Resource Library

Massachusetts Genetic Program

Massachusetts Department of Health

Boston, Massachusetts

This video library contains a large variety of genetics and inherited diseases topics. There is no charge for the use of materials and mailings throughout the United States. Bookings can

be made on school stationery and must be made two weeks in advance of showing.

Resources: Additional Readings

A. Angier, N. "A Stupid Cell With All the Answers." Discover. 1986, 7(11):71-83.

B. Ayala, F.J. "Whither Mankind? The Choice Between a Genetic Twilight and a Moral Twilight." Amer. Zool. 1986, 895-905.

C. Carey, J. "The Genetic Age." Business Week. 1990, 68-83.

D. Cunningham, James C. "A Guide to Cystic Fibrosis for Parents and Children," C.F.F. 1988.

E. Dean, Jurien. "Sickle Cell Anemia: Molecular and Cellular Bases of Therapeutic Approaches." New England Journal of Medicine. Oct 5, 1978, 752-753.

F. Gaston, Marilyn H. "Slckle Cell Disease: An Overview." Seminars in Roentgenology. vol XXII, 1987, 150-154.

G. Gibbons, A. "Biotechnology Takes Root In The Third World." Science. 248, 962-963.

H. Gonick, L. The Cartoon Guide to Genetics. Harper and Row, 1983.

I. Jaroff, L. "The Gene Hunt." Time. 1989, 62-71.

J. Lewin, B. Genes. 1987, John Wiley and Sons, New York.

K. Singer, S. Human Genetics. W.H. Freeman and Company, New York.

CHAPTER 6

SUMMARY AND CONCLUSIONS

Introduction

Secondary school students are being inadequately prepared in their understanding of genetic diseases. This statement has been supported by studies of high school students (G.J. Stine) and of college students (Thomas Mertons). Most young people will come in contact with genetic diseases only through personal experiences and/or family and associate relationships. In order to overcome this educational gap, improved genetic diseases teaching expertise and accurate teaching curricula, are essential to promote student genetic diseases comprehension, decision-making and behavioral sensitivity.

The following accomplished goals (with special emphasis on numbers 5 and 6) were the objectives of this presentation:

1. To show the importance of genetic diseases curriculum and instruction in the secondary school classroom.

2. To explain some of the challenges and difficulties that

face teachers in the teaching of genetics in general.

3. To assess science educators' level of genetic diseases knowledge and understanding.

4. To ascertain which areas of genetic diseases instruction, are lacking in biology and science classrooms.

5. To design a curriculum format based on assessed needs, that will enable biology and science teachers to produce their own genetic diseases curricula.

6. To structure a staff development manual for genetic diseases teacher education.

Summary

Before discussing the genetic diseases teaching issues, it must be pointed out that the task of teaching genetics in general, is faced with many obstacles. As a result of these challenges and hurdles, many biology and science teachers devote little if any, time to the subject.

There are a variety of reasons for this and a variety of genetic teaching difficulties:

A. Students do not have a meaningful comprehension of basic Mendelian genetics.

B. The colleges and universities are inadequately preparing teachers to teach genetics.

C. There are not enough teacher materials and resources for the teaching of genetics.

D. Teaching strategies for genetics, consist of an overabundance of factual material with very little student analytical time.

E. Genetics related field trips are not considered by some to be an intergral part of school work.

F. Many secondary school level biology and life science text books which contain ambiguous and incorrect genetic terminology, are source of student confusion.

G. Students' misconception of genetics prior to taking a course, may interfere with their subject comprehension.

H. Not enough time is allotted in the sequences of biology courses, to cover genetics.

I. Some students have basic learning (comprehension and

retention) difficulties in genetics.

J. The relevancy of genetics to the evironment, is being played down or excluded in many courses.

These genetics teaching challenges are real and can be enormous stumbling blocks to classroom instruction. It is for this reason that diverse teaching guides and subject curricula, are imperative in science education.

Twenty-six biology and life science teachers were selected randomly from the Summer Biotechnology Teachers' Program at Boston University (a series of summer teaching workshops), in order to determine the teacher genetic diseases comprehension levels and the accessibility and utility of genetic diseases curricula. For confidentiality, the teachers did not give their names, but were assigned numbers (1 to 26). All of the teachers lived in and taught in the Greater Boston Area. Nineteen teaching communities from this area, were represented by the teachers. Each voluntarily answered 25 multiple choice and open-ended questions, verbally from a Genetic Diseases Interview Questionaire which was constructed for this study. Questions 1-5

on the questionaire, centered on the personal career history of the teachers; questions 6-10 centered on general genetics knowledge; questions 11-22 centered on four specific genetic diseases (Cystic Fibrosis, Tay-Sachs disease, Sickle Cell Anemia and Thalassemia); questions 23-25 centered on science curriculum and instruction.

The twenty-six teachers who were from several racial and ethnic backgrounds (Caucasian, African-American, Hispanic and Asian-Americans), were interviewed using a tape recorder. The teachers' answers were scored for correctness and correlations by the STAT statistical analytical program.

Teaching Experience

The more years of science teaching experience the teachers had, the greater the chance that an understanding of genetic diseases had been acquired throughout those years.

Accurate details (symptoms; causes; treatments; persons affected) of specific genetic diseases, were lacking by many of the teachers, including some of the experienced teachers (20 years or more). The concern here, however, is that the newer

teachers to the science classrooms, may have a greater need for assistance in the teaching genetic diseases. Least experienced teachers are more vulnerable to poor performance in science teaching, when there is little or no support in professional and subject area development.

Schools and Genetic Diseases Curriculum

The probabilty of the presence of a genetic diseases curriculum, were slightly higher in schools located further from the Metropolitan Area (thirty miles or over), than in schools closer to the Metropolitan Area (within thirty miles). Greater attention and available finances are often devoted more extensively to specialized curriculum, in many of the outer metropolitan and suburban communities. This is due to a multitude of reasons concerning inner city education, which include the urban population increase, municipal and state funding and local politics. These conditions, however, are not unsurmountable.

Curriculum Access:

Those teachers (n=14) who did have a genetic diseases curriculum or a genetic diseases unit in an already existing

biology or science curriculum, in their schools, excelled in their overall understanding of genetic diseases. Those teachers also, reported that they were imparting this information to their students. For further reference, see Chapter Four.

Staff Development

The majority of the teachers (92 percent) responded affirmatively when asked if they would like to learn more about genetic diseases. In particular, they requested more information on the following six specific genetic diseases which are arranged in order of the number of requests: Thalassemia; Sickle Cell Anemia; Tay-Sachs Disease; Cystic Fibrosis; PKU; Huntington's Disease.

The G.D.C.S.F. Teaching Manual

Educators are aware that we are living in a time of change. Therefore, in order to prepare students to enter into the next millennium as enabled, competent citizens of the world, our educational will have to be restructured. New innovative school practices and programs must be developed and disseminated. It is in this spirit of restructuring education that the Genetic Diseases

Curriculum Strategy Format has been facilitated.

The construction of the Genetic Diseases Curriculum Strategy Format (G.D.C.S.F.), addresses classroom needs and ideas expressed by the teachers who participated in the Genetic Diseases Questionaire.

Some of the expressed instructional needs were: (1.) To acquire more detailed information on specific genetic diseases (2.) To have a discussion framework for societal and personal issues concerning genetic diseases (3.) To explore genetic engineering and biotechnology methods (4.) To familiarize themselves with the medical and personal needs of those who are affected with a genetic disease (5.) To acquire historical information on genetic diseases.

The G.D.C.S.F. which is both a staff development tool and a teaching instrument, was designed to increase scientific literacy and awareness of genetic diseases, to promote the building of positive student self-esteem through learning and to improve student decision-making skills. It is a teacher's manual used by the teacher, to "customize" a junior or senior high school genetic

diseases classroom program. It can be utilized within an already existing biology or science curriculum or as the foundation of an entire inherited diseases course. The timing and methodoloy for incorporating the manual's genetic diseases teaching strategies, varies with the instructor's teaching mode and the students' learning styles. However, several suggestions and "Notes to the Teacher" are included to assist in the introduction, presentation and timing of genetic diseases.

There are five basic genetic diseases teaching units in the G.D.C.S.F. With the exception of Unit I, the unit may be taught separately, in combination or consecutively. The units are as follows:

Unit I (Basic Information) presents fundamental concepts of cells and chromosomes. This unit is essential for an effective understanding of the basic mechanisms and principles of inherited disorders and should be presented as a required, premier unit. It, also, was designed to be used, if possible, in combination with a classroom biology or life science textbook.

Unit II (Let's Talk About Genetic Diseases History) presents

historical information and events concerning genetic diseases. It is a historical trivia bank design to stimulate student research.

Unit III (The Nature of the Disease) presents an overview of the catagorizing of genetic diseases and explores four specific genetic diseases (Cystic Fibrosis; Tay-Sachs Disease; Sickle Cell Anemia; Thalassemia--Alpha and Beta) in detail.

Unit IV (The Human Side of Genetics--Decision-Making) introduces students to some of the ethical, moral and metaphysical issues surrounding genetic diseases and genetic research.

Unit V (Resources) contains a listing of genetic diseases foundations and agencies with available instructional materials and services for classroom teachers.

The Teacher's Challenge

The promotion of positive student attitudes towards genetic diseases, depends on the curriculum and the teacher's attitude. In order for teachers to foster favorable attitudes, they (the teachers) must be prepared with content information (knowledge of the genetic diseases) and with the tools of discerning life-

threatening diseases. Staff development instruments like workshops, conferences and supportive networking, are needed to assist teachers in class preparations. Good science teaching makes the difference in how students view genetic diseases in relation to themselves, their community and affected family members, classmates and friends.

Teacher training in genetic diseases education (which the G.D.C.S.F. advocates), is essential due to the following real-life situations:

Teachers are faced with the reality of children affected with genetic diseases, being placed in their classrooms. One in 20 Caucasians in America, carries the Cystic Fibrosis gene. One in 1,600 Caucasian births will have CF. One in 25 American Jews carries the Tay-Sachs gene. When both parents carry the TS gene, there is a 1 in 4 (25 percent) chance with each pregnancy, that the child will have the Tay-Sachs Disease. One in 10 African-Americans carry the Sickle Cell gene. One in 600 Blacks and 1 in 1,000 to 1,500 Hispanics, Arabians, Greeks, Sicilians and Turks will inherit Sickle Cell Anemia. Each year in the United States,

over 2,500 people of Southern Asian, Middle Eastern, Italian and Greek descent, are hospitalized for the treatment of Thalassemia. With the present statistics, for some teachers, teaching these children can be an unsettling experience. However, with proper understanding of genetic diseases, a well-prepared teacher is a valuable link in the total care of the child. Especially with the use of a prepared curriculum, the teacher is able to establish an equilibrium of theory and reality.

Isolation and loneliness occur when a young person does not understand and/or can not communicate about his or her genetic disease. Genetic diseases exert a defining effect on the affected person's self image. Some of the effects are:

A. The person feels that he or she has a less adequate ancestry than others do.

B. The person will try to hide his or her genetic disease status. Many reject treatment because of the urgent need to be "normal".

C. People with genetic diseases sometimes, carry a tremendous amount of guilt.

The primary purpose of including the four specific genetic diseases in the G.D.C.S.F., is to enable teachers to understand the commonality of occurrence of these diseases and to communicate this to the students. Cystic Fibrosis, Tay-Sach Disease, Sickle Cell Anemia and Thalassemia are representative of the ethnic and racial population distribution in the United States public education systems. A typical example of this, is found in the Boston Public School System Student Enrollment Distribution (Boston Public Schools Fact Sheet--March,1992). Of the 57,525 students enrolled for the 1992 school year, 48 per cent were Black, 21.6 per cent were White, 9 per cent were Asian, 21 per cent were Hispanics and .4 per cent were American Indians. There is genetic variety in human beings and no one group or individual is exempt from potential genetic disease involvement.

Another situation teachers must face is that since teenagers are having more babies (despite available birth control methods), the chances of teens having babies with genetic diseases, is increasing. The Children's Hospital of Boston, Genetic Screening Clinic (a Harvard University Medical School teaching facility) is

reporting a rise in the number of teenagers seeking genetic advice and counseling. The majority of these young parents come with their parents or grandparents, after they (the teens) have had a baby with a genetic disease or disorder. It would be more beneficial to all those involved, to get this information to the teens prior to fetal conception. Some of the genetic diseases situations of young mothers and fathers could be avoided with proper genetic diseases education in secondary school. Teachers with proper training, could remove some of the mysterious and erroneous communications about genetic diseases.

Conclusions

As outlined in Chapter Two, genetics is not an easy subject to teach to secondary school students--even when the teacher has a genetics expertise--, and those challenges which pose as obstacles are also present when teaching genetic diseases. As a result of this, some students are being overwhelmed with complex genetic diseases instructional detailed; some students do not retain the genetic diseases information received; some students receive the information as abstract and do not process it as

reality; some students receive little or no genetic diseases classroom information. The reasons behind this science dilemma, must be dealt with from three focal points. The first is the question of teacher knowledge and understanding of genetic diseases. The second is the question of why genetic diseases instruction is vital to the secondary school classroom. Finally, the third is the question of the importance of genetic diseases curriculum presence in science programs.

Teacher Knowlege and Understanding

The way to acheive a flourishing society, is through the educational development of its children. A quality science education contributes to the legacy of positive lives. However, too many high school students are passing through biology and life science classes with little or no knowledge of genetic diseases. What is holding genetic diseases instruction prisoner? A portion of the answer can be found in teachers' knowledge/understanding, education/training and in motivation/perception.

The majority of teachers are diligently teaching and exploring the basics of the biological sciences with their students.

However, explanations of the multitude of genetic diseases require a special skilled knowledge and understanding of the principle and mechanisms of inheritance. Some life science and biology teachers have this understanding and effectively convey it to their students. Some life science and biology teachers have the knowledge and understanding of genetic diseases, but find it troublesome or awkward to simplify the subject into terms the students can comprehend. These teachers unintentionally intimidate and discourage students from further genetic diseases exploration. Some life science and biology teachers are not familiar with the subject of genetic diseases--the genome; the transmission; the manifestations; the testing; the treatment ; the counseling. In this case, students are not getting the genetic diseases information due to ommission or the information is being glazed over due to teacher's genetic diseases unfamiliarity.

A lack of teacher training and staff development in genetic diseases, are contributing factors in the lack of teacher knowledge and understanding. Many college and university teacher programs do not provide or require any extensive classwork in genetics or

genetic diseases for their matriculating students. Also many science staff development programs and in-service workshops and seminars, are lacking in educating teachers to this progressively growing field of study. As voice by the majority of the teachers in this study, life science and biology teachers are becoming increasingly aware of the deficit in their genetic diseases educational background. Some pointed out the inequities in state and city funding for teacher programs.

For those teachers that do understand genetic diseases and can apply their knowledge to active classroom strategies, teaching motivation is paramount. Teachers must encourage themselves to overcome their own personal prejudices of human achievement. A teacher's perception of his or her students or the students' social or economic backgrounds , will influence how much effort he or she will put into broadening the genetics study base. Unfortunately, many urban secondary school students are lacking in genetic diseases education because of teachers' preconceived assumptions.

> Sometimes teachers don't ask enough of students. They feel sorry for some youngsters because of their socioeconomic or racial or ethnic background and decide they (the students) won't be able to do real work. So they teach a watered-down curriculum and short change youngsters who could learn if given a chance.[21]

Children in urban centers are not getting a fair deal in terms of books, supplies and subject coverage expansion.

The Importance of Genetic Diseases Instruction

The importance of genetic diseases being taught to secondary school students, can be paralled to the sought after goal of education in general. This goal is to educate children to become successful adults--successful meaning functioning, literate, competitive and aware. The providing of genetic diseases information promotes this success.

In the long term--that is decades following their classroom participation--students will not remember all the thousands of detailed facts in traditional life science and biology courses. People remember what they need in life. Therefore, a wholistic approach of preparing a child's thinking is the cornerstone of a successful education. From this perspective, students retain the

following aspects which will be discussed in terms of their relationship to genetic diseases instruction:

The first outcome of a successful education is the promotion of positive self-esteem in student thinking. Teachers' behaviors have a definite role in promoting student self-esteem. Opportunities for recognition of students' unique talents, skill levels and abilities, as well as a sensitivity to individual student's needs, are all evident in good teaching methods. Teachers must promote the belief that each student has the capacity to learn and master basic skills.

Educators have tremendous clout in making a child's life miserable or joyful. Their responses can either humanize or dehumanize; encourage or humiliate; heal or hurt. Teachers must develop through training, a sensitive approach to the youth that sit before them. One of the ways is an awareness of the everyday realities that face their students. Genetic Diseases are part of their reality. A reality that does not go away if ignored. In fact, the complication of sorrow is multiplied when the issues are not faced. Many young people are dealing with family, friends or

themselves being affected with a genetic disease. For student emotional survival, there is an urgency for teachers to expand their science classroom repertoire to include genetic diseases education.

The best way to destroy self-esteem in a classroom setting, is to allow students to become isolated. The teaching of genetic diseases builds a child's awareness of his own uniqueness, and assists in eradicating student isolation. Each of us has inherited one-of-a-kind combinations of genes which tell us of who we are and who our offspring are to be. Any of the genetic complications that can result from these combinations, are also apart of our uniqueness. Genetic diseases education fosters a tolerance for and an appreciation of individual differences, by valuing diversity.

The second outcome of a successful learning process is the mastery of the skill of knowing how to access information. This knowing where and how to get needed information is just as important as acquiring facts. It requires reasoning skills. Genetic diseases education provides students with the tools to explore and analyze the logical sequencing of information related to the

mechanisms of inherited diseases. Young people (the future adults) would not be so overwhelmed by circumstances if they had methods to find information and to decode the information's meanings.

The third outcome a successful education is that students have been made aware of the world's inter-connection. In a global society, teamwork is a necessity for planetary survival. Each racial and ethnic group has its own set of genetic difficulties. All groups must be knowledgeable of themselves and each other, in order to be fully committed to the whole human population. Genetic diseases education expands the horizons (and borderlines) of students to help them see themselves as a part of the larger order of life.

The Need for Genetic Diseases Curriculum

Concerning the current state of biology and life science education, traditional science curriculum is not meeting the needs of secondary school students or teachers. Most science curricula are outdated as they contain little or no reference to genetic diseases. This is what was expressed by the teachers interviewed

in this work. Even textbooks are lacking in their coverage of genetic diseases. Education must be relevant and accessible.

Biology and life science teachers require teaching instruments to enable them to sensitively and compassionately cover specific genetic diseases, without alienating those students affected. Many teachers stated that they desired retraining programs.

Student populations are changing. Children with genetic diseases--often with physical manifestations--are being mainstreamed into the regular classroom. Classroom education must also address the fact that both teenage pregnancy and the rate of birth disorders (including inherited diseases) in this age group, are increasing, especially in urban centers. Students look to their teachers for informational assistance. The answer is to create new genetic diseases curricula or to incorporate genetic diseases outlines into the framework of present life science and biology curricula.

In 1990, The Institute of Social Research at the University of Michigan, compared the averages in which students in the United

States and Japan, spend their time (hours per week). The results were as following:

In School:	U.S.--26.2	Japan--41.5
Studying:	U.S.--3.8	Japan--19.0
Reading:	U.S.--1.6	Japan--3.3
Television:	U.S.--14.2	Japan--17.7

United States high school students due to a variety of reasons, justified or unjustified, spend less time in school, studying and reading than other developed nations. Japan is just one example of a comparison nation. What this means to the U.S. educator is that classroom time and attention time of U.S. students, is short and precious. Every hour of the school week , should be utilized to the utmost. What is said and read in the classroom and contained in the homework assignments, must be precise and in-depth. In order to cover genetic diseases in short segments of time, a curriculum guide is necessary to complete all objectives. The Genetic Disease Curriculum Strategy Format has been designed in this work, as is a manual for student learning and staff development. It is for the constructive utilization of

available instructional time, producing the favorable results of student and teacher comprehension the dynamics of genetic diseases.

In Summation

The urgency for more teacher training and educational reform in genetic diseases, is expressed by Ola Mae Huntley, in her own personal account, " A Mother's Perspective.", of the trials she had with a genetic disease (Hastings Center Report. Los Angeles, California). Her words are a fitting conclusion to this study.

> I am the mother of five children, three of whom have Sickle Cell Anemia. At the time my husband and I married, we had never heard of Sickle Cell Anemia.
>
> After our second child was diagnosed as sickle-cell-anemic, a well-meaning but informed doctor assured me that, since we had one normal child and one with Sickle Cell Anemia, our future children would be normal, purely on the basis of numerical chance. Our third and fourth babies came close together; before the third was diagnosed the fourth was born. The fifth was a "mistake"--but a happy one. She does not have the disease.
>
> Our sickle cell anemic children are now young adults. Only rarely can we be home together as a family. Usually one or two, sometimes all three, are in the hospitals being treated for acute disease crises or for the debilitating effects of the disease. This is a way of life, or I should say , a way of existence.
>
> For twenty-five years we have watched doctors repeat the sme procedures and the same medications--only with the promises of temporary relief. I have watched my children,

young and frightened, face major surgery for the removal of their gall bladders.

Because this is a genetic disease, my two normal children are 'carriers'. This means we have to counsel them regarding their choice of a mate. If they marry another Sickle Cell trait carrier, they will either have to decide not to have children or risk the possibilty of passing on the disease to them.

In my twenty-five years as a mother very little has changed. The current state of medical art is to treat the symptoms, but little has been done about treating the cause. Today some birth can be prevented by advising couples who are carriers to make the sad choice of not marrying or, if they do marry, to refrain from having children. However, couples who are unaware of the danger of reproducing a child with a genetic disease, or who decide to take the numerical chance that one or two children will be normal, run the risk of bringing children into a life of pain and misery.

Though my emphasis is essentially on Sickle Cell Anemia patients, the populations with Tay-Sachs, infant Glaucoma, childhood Diabetes, Down Syndrome and Hydrocephalus face a similar future. Merely relieving the symptoms of these devastating genetic diseases is like putting a very small Band-Aid on a very large wound.[22]

The responsibility of education is to be committed to the improvement of the quality of life. This committment extends to include the vitally needed knowledge and understanding of teacher expertise in and student comprehension of genetic diseases.

APPENDICES

APPENDIX A

LISTING OF GENETIC DISEASES FOUNDATIONS AND AGENCIES

The following foundations and agencies provide some very important literature concerning the genetic diseases to be covered in this study:

The Boston Sickle Cell Center:

The Boston Sickle Cell Center, founded in 1972, is a comprehensive program that offers free education, counseling and testing services throughout the greater Boston Area. It is a central and leading organization of the many sreening and comprehensive Sickle Cell Anemia centers that are throughout this country.

The main offices are located in the Boston City Hospital. However, the program's activities are carried out in local hospitals, health clinics and universities. All sickle cell testing and programs are at no cost to the people utilizing the services. The BSCC also, provides educational programs for community groups and health-related classrooms and for genetic counseling to all age groups. All educational materials they supply, give an overview of the complexity of Sickle Cell Anemia.

The following publications from the Boston Sickle Cell Center, will be employed in this study:

1. "Learning About Hemoglobins--AC, CC,SC."
2. "Sickle Cell Trait and Sickle Cell Anemia."
3. "Your Child and Sickle Cell Anemia."
4. "Tell Me About G6PD--Glucose-6-Phosphate Dehydrogenase."
5. "What Should We Do."

The Cystic Fibrosis Foundation:

The Cystic Fibrosis Foundation provides numerous booklets and information guides (including Their own national newspaper called "The Commitment"). Most of their publications are directed towards those individuals and families who are actually affected by the disease. An example of this is a 95-page, large-print, easily understood manual entitled "A Guide To Cystic Fibrosis For Parents and Children".

It is rewarding to find that the C.F. Foundation considers teachers as "caregivers". Both the United States C.F. Foundation and the Canadian C.F. Foundation distribute a publication called "A Teacher's Guide To Cystic Fibrosis". Many teachers' questions are

answered here. Also available to teachers, is a handbook entitled "Talking With Children With A Life-Threatening Illness". This particular work is concerned with the preparing of teachers to deal with life-threatening genetic diseases and the instructing of teachers on the specific issues that relate to the classroom environment.

The March of Dimes

Birth Defect Foundation:

Although The March of Dimes is concerned about the screening and counseling of specific genetic diseases, their main focus seems to be towards the prevention of all birth defects, by the elimination of environmental factors. Smoking, drugs, the worklpace, nutrition, alcohol drinking and pre-natal care are the aspects that The March of Dimes relates to pregnancy. Since 480,000 teenagers give birth each year (that is 1 in 8 U.S. births), The March of Dimes puts out lots of literature geared to this youthful population.

The March of Dimes has a "Catalogue of Public Health Materials" which contains listings of booklets, genetic speaker series, informational sheets, educational kits, films and posters.

The Massachusetts Department of Public Health:

"The Genetic Resource" is produced by The Massachusetts Department of Public Health. It is a free referral guide to genetic organizations and services. This bi-annual journal provides information on current research developments.

The National Tay-Sachs and Allied Diseases Association:

This National Tay-Sachs and Allied Diseases Association publishes pamphlets for those people who need basic information about these genetic diseases and who need help through disease-related crises. The Association's main emphasis is on screening. They will provide posters and facts sheets, upon request, to any public educator.

APPENDIX B

WRITTEN CONSENT FORM

"An Investigation Into the Teaching of and the Curriculum Development for Inheritance and Genetic Diseases on the Secondary School Level."

To The Participants:

I am Betty Bridgforth, a doctoral student in Education at University of Massachusetts/Amherst. I am interviewing science and health teachers in the Greater Boston Area, to assess the need for effective, genetic diseases curriculum. You are one of the twenty-six, randomly chosen participants.

As a part of this study, you are asked to participate in an interview which will last approximately one hour. Questions will range from multiple choice to open-ended sentences. The interview contains questions concerning: general genetic diseases information; four specific genetic diseases; genetic diseases curriculum.

My goal is to analyze the interviews, in order to understand teachers' knowledge of and experience with genetic diseases. From

the compiled results, a Genetic Diseases Curriculum Strategy Format will be created. This educational tool will allow teachers to develop their own genetic diseases curriculum according to individual classroom needs.

Each interview will be audio-taped and later transcribed by me. To assure confidentiality, each participant will be assigned a number. Under no circumstances will names of people, be used. Your school will be referred to as a "Greater Boston Area" school, only. The gathered information will be used in my doctoral dissertation and may also, be used in journal articles, workshops for teachers and books.

I wish to encourage your participation in the study. Should you consent, you may withdraw at anytime. You may also, wthdraw your consent of having specific excerpts in the interview, used in printed materials or oral presentations. If the interview were to be used in a different way, other than previously stated, you would be contacted for additional written consent.

By signing this form, you are assuring me and the University of Massachusetts/Amherst, that you will make no financial claims for

the use of the materials in your interview. Also, by signing, you are stating that no medical treatment will be required by you from the University of Massachusetts/Amherst, should any physical injury result from participating in these interviews.

I.....have read the above statement and agree to participate as an interviewee under the conditions presented above.

.....
Signature of the Participant

.....
Date

.....
Interviewer

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