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# Success of a Short-term Genetics Educational Intervention for Nursing and Dietetic Students

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## **Abstract**

Allied health professionals are being encouraged to prepare for the impact that advances in genetics knowledge and technology are expected to have on all aspects of health care. As a step towards achieving this goal, a web-based tutorial on basic genetics and an hour-long presentation with case-based discussion on the genetics of diabetes were incorporated into two undergraduate nutrition courses, one for nursing and one for dietetic students. Results obtained using a pretest/posttest quasi-experimental design support the hypothesis that incorporating genetics into a pre-existing nutrition course can successfully increase students' knowledge of genetics and confidence in their ability to provide genetic-related services, such as eliciting family medical history information and making appropriate referrals to genetic professionals. The educational intervention was positively rated by the majority of students, and most students agreed that genetics is important for their future career and should be integrated into multiple courses.

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## Table of Contents

I.	Introduction.....	3
II.	Background.....	4-8
	a. Genetics and Allied Health Professions.....	4-6
	b. Study Purpose.....	6
	c. Educational Strategies.....	6-8
III.	Methods.....	8-15
	a. Setting and subjects.....	8
	b. Procedure.....	8-9
	c. Web-based tutorial.....	9-10
	d. In-class presentation.....	10
	e. Knowledge.....	10-11
	f. Likelihood and confidence.....	11
	g. Attitudes.....	11
	h. Other variables measured.....	12
	i. Reliability and validity.....	12-13
	j. Data collection and analysis.....	13-15
IV.	Results.....	15-23
	a. Demographics and educational background.....	15
	b. Knowledge Scores.....	16-17
	c. Confidence and likelihood ratings.....	17-18
	d. Attitudes about genetic topics of importance.....	18-19
	e. Attitudes about the educational intervention.....	20-22
	f. Comparison of participants based on completion of the study.....	22-23
V.	Discussion.....	23-33
	a. Genetics knowledge.....	23-25
	b. Confidence in performing genetic related services.....	25-27
	c. Attitudes on genetic topics of interest.....	27-28
	d. Attitudes about the educational intervention.....	28-29
	e. Incorporating genetics into allied health curricula.....	29-31
	f. Study limitations and strengths.....	31-32
	g. Applications and future directions.....	32-33
VI.	Bibliography.....	34-38
VII.	Tables.....	39-44

## Table of Contents (continued)

VIII. Appendices.....	45-96
a. Appendix A: Goal and learning objectives for the tutorial.....	45
b. Appendix B: Case example from the tutorial.....	46
c. Appendix C: Tutorial questions and answers.....	47-51
d. Appendix D: Pedigree information.....	51-54
e. Appendix E: PowerPoint lecture.....	55-62
f. Appendix F: Case-based problems.....	63-70
g. Appendix G: Reference material for cases.....	71-90
h. Appendix H: Knowledge test.....	91-92
i. Appendix I: Likelihood and confidence (both questionnaires).....	93
j. Appendix J: Genetic topics of importance (both questionnaires).....	94
k. Appendix K: Evaluation of intervention (post-questionnaire).....	95-96
l. Appendix L: Demographic questions (pre-questionnaire).....	97

## List of Tables

Table 1. Demographics of participants in the two courses.....	39
Table 2. Percent of students who responded yes to statements..... regarding previous genetics education	39
Table 3. Average test scores $\pm$ SD, percent change in scores following..... the educational intervention, and relative percent improvement	40
Table 4. Change in average total likelihood and average total..... confidence ratings	40
Table 5. Changes in likelihood and confidence ratings for each..... of the 12 genetic related services	41
Table 6. Top 5 most important genetic topics before and after the..... Intervention	42
Table 7. Evaluation: Incorporating genetics into the curricula.....	43
Table 8. Evaluation: Web-based tutorial.....	43
Table 9. Evaluation: Class presentation.....	44
Table 10. Evaluation: Case scenarios.....	44

## Introduction

Increases in genetics knowledge, media focus, and market forces will eventually require all health care providers to be knowledgeable about genetics, regardless of their specialty area, practice setting, or role.<sup>1,2</sup> Genetics is already beginning to play an increased role in health care, largely due to the expansion in the number of genetic tests and therapies that are becoming available.<sup>1-3</sup> The demand for genetic services continues to grow as more information becomes known about how genetic factors contribute to the development of common diseases.<sup>1, 3-5</sup>

Common diseases, including coronary artery disease, hypertension, obesity, diabetes mellitus, and cancer, are known to be caused by both genetic and environmental factors.<sup>1</sup> A person's susceptibility to common diseases can often be determined by taking a family medical history and by the identification of genetic variations or mutations believed to contribute to disease development.<sup>1,6</sup> Early identification of risks can lead to disease prevention through the appropriate use of medication, prophylactic surgery, and/or recommendations for dietary and lifestyle modifications.<sup>5-7</sup>

Unfortunately the potential health benefits of genetic discoveries will only be realized if health care professionals have the genetics knowledge and related skills needed to incorporate this information into their practice. It is therefore critical for all health care professionals to have an understanding of genetics and how it may impact their clinical practice.<sup>2,8,9</sup>

## **Background**

### GENETICS KNOWLEDGE AND EDUCATION IN ALLIED HEALTH

Allied health professionals, including nurses, often work with individuals who have genetic conditions, yet most have little formal education in genetics.<sup>10-15</sup> Despite their lack of genetics education, allied health professionals perform a number of genetic related services such as eliciting family medical history information, assessing genetic risk for disease, discussing the genetic component of conditions with clients, and facilitating decision making involving genetic information.<sup>10,16-19</sup>

In 1998, the Human Genome Education Model Project II sponsored a cross-sectional survey of 3600 allied health professionals in six different disciplines including dietetics.<sup>10</sup> Although over 50% of the respondents reported taking family medical histories, only 21% reported high confidence in their ability to elicit genetic information. The vast majority (70% or more) from each discipline reported discussing the genetic component of conditions with at least a few clients, but only 16% indicated high confidence in their ability to do so. Only 30% of respondents felt highly confident counseling clients regarding decisions about genetic testing, and less than 20% were highly confident in their ability to refer clients for genetic services. Confidence was significantly higher among individuals reporting formal genetics education compared to those with little or no formal education in genetics. This suggests that by including genetics in allied health training programs, confidence in performing genetic related services will increase among allied health professionals.

Although the HuGEM survey did not include nurses, there is an extensive body of literature documenting the lack of sufficient genetics education in nursing programs and

the need for nurses to incorporate genetics knowledge into their practice.<sup>12,14,17,20-22</sup> One recently published study of oncology nurses revealed that although nearly half of the respondents had received patient inquiries regarding cancer genetics, only 35% were aware of referral resources and only 26% had made such referrals.<sup>17</sup>

The need to include genetics in training programs for nurses has been recognized since the 1960's, but significant efforts to integrate genetics into nursing curricula did not begin until the 1980's.<sup>8,23,24</sup> Although these efforts have accelerated since the initiation of the Human Genome Project (HGP) in 1991, continued efforts are needed to increase genetics knowledge and skills among nurses.<sup>8,13,25</sup>

The American Dietetic Association (ADA) has also recognized the importance of genetics.<sup>27</sup> Former ADA president, Ann Coulston, has encouraged dietetics professionals to "prepare for, participate in, and benefit from the study of human genetics".<sup>15</sup> As a result, the Commission on Accreditation for Dietetics Education added genetics to the 2002 knowledge requirements for undergraduate training programs.<sup>28</sup> However, there are no guidelines specifying which genetic topics should be included.

To guide the development of genetics curricula for non-genetics health professionals, a number of publications provide general recommendations. Among these are "Core Competencies in Genetics Essential for All Health-Care Professionals" published by the National Coalition for Health Professional Education in Genetics (NCHPEG), and "Genomic Competencies for Public Health Professionals" developed by the Centers for Disease Control and Prevention (CDC).<sup>2,29</sup> Recommendations and suggestions regarding the content of genetics curricula specific to nursing and dietetic professionals have also been published.<sup>1,9,16,17,30-35</sup>

A wide variety of strategies have been used to incorporate genetics in undergraduate and graduate nursing curricula.<sup>15, 31, 36-42</sup> One approach has been to include a small amount of genetics content into a number of courses within the nursing curriculum.<sup>42</sup> Given the important role that genetic and nutritional factors play in the development of common complex diseases, a nutrition course can be an appropriate course for incorporating genetics.

The importance of this study is illustrated by the following two findings. There are no published reports describing or assessing the effectiveness of including genetics as part of a nutrition course for nurses. There have not yet been outcomes published on the inclusion of genetics in dietetics curricula.

#### STUDY PURPOSE

The purpose of this study was to evaluate the effect of a short-term genetics educational intervention on nursing and dietetic students' knowledge of genetics, confidence in their ability to perform a number of genetic related services, and their attitudes regarding various genetic-related topics and the educational methods used during the intervention. The hypothesis tested in this study was that student's knowledge of genetics and their confidence in their ability to perform genetic related services will increase after completing the genetics educational intervention.

#### EDUCATIONAL STRATEGIES

There are many potential educational methods and theories that can be used when designing an educational intervention, but there are few well designed research studies

testing the effectiveness of such interventions.<sup>43-46</sup> Despite their limitations, research studies suggest that case-based and problem-based learning strategies can be effective ways to deepen understanding of a subject, enhance cooperative learning, develop higher order thinking skills, increase students' confidence, and aid in making functional use of knowledge.<sup>47-55</sup> These learning methods have also been viewed positively by students, who report that case-based problems increase their interest, enjoyment, and understanding of the subject.<sup>46,47,56,57</sup> Because the ultimate goal is for students to be able to utilize genetic skills and knowledge in clinical practice, case-based problems were incorporated as part of the educational intervention.

Students from a variety of health care disciplines have indicated that case-based and problem-based learning strategies are more enjoyable and effective in linking theory to practice when compared to didactic methods, such as tutorials and lectures.<sup>56,58-60</sup> However, many of these students also admit that didactic teaching methods are more effective for knowledge acquisition.<sup>59,60</sup> College freshman have also expressed the opinion that traditional didactic teaching strategies are the most efficient methods for learning basic concepts.<sup>61</sup> One study of nursing students found that incorporating multiple teaching strategies was superior at increasing knowledge when compared to lecture only.<sup>62</sup> Based on evidence from these studies, the best educational intervention may incorporate both didactic and case-based strategies. There have been successful educational interventions for students in health care professions that have utilized both didactic and case or problem-based strategies in their design.<sup>48,61</sup>

In order to provide students with the basic knowledge required for the case-based problems, two didactic teaching strategies were used as part of the educational

intervention. A self-directed, web-based tutorial was included for the following reasons; 1) faculty members were uncertain how much students already knew about genetics, and a self-directed tutorial allows students to learn or review basic concepts at their own pace, 2) self-directed learning modules have been effective at increasing knowledge among practicing nurses,<sup>63-65</sup> 3) electronic information can be easily updated without the added cost of reprinting materials, and 4) resources on the internet allow for easy access to more in depth information on topics of particular interest. The second didactic strategy was a PowerPoint lecture, which was included to impart basic knowledge on diabetes and genetics.

## **Methods**

### **SETTING AND SUBJECTS**

The educational intervention and study evaluation took place during winter quarter 2003 at a Midwestern research university. The university has a total enrollment of over 33,000 students, including 7,300 graduate and professional students. Eligible participants included all students enrolled at the time of the study in a medical nutrition therapy course, required for all dietetic undergraduates, and a general nutrition course that is required for undergraduate nursing students. The medical nutrition therapy course was the second in a three-quarter series while the nutrition course for nurses is only a one-quarter course.

### **PROCEDURE**

All students who were present on the day of the first examination were provided a written document and short verbal introduction describing the study. Informed consent

was signified by completion of the pre-test and pre-questionnaire. Students were instructed to complete the web-based tutorial one to two weeks later. The tutorial was a required assignment in the medical nutrition therapy course and was included as an extra credit assignment for the nursing nutrition course. Approximately one to two weeks later, the in-class presentation on genetics and diabetes was given during one of the regular class periods. The nursing students completed the post-test and post-questionnaire in class immediately following the genetics presentation. The dietetic students completed the post-test and post-questionnaire in class two days later due to an unanticipated reduction in the amount of class time allotted the day of the presentation.

After turning in the study questionnaires and tests, students were given a coupon to a local eatery regardless of whether they chose to participate. In compliance with IRB approval, students could choose not to participate without the knowledge of other students or the instructor, and they were not penalized in any way.

#### WEB-BASED TUTORIAL

The primary author developed a web-based tutorial covering four main topics: 1) basic genetic principles, 2) the use of pedigrees as part of the family history taking process, 3) risks associated with various patterns of inheritance and clues to recognize these patterns, and 4) general recommendations for when and how to make a referral to genetic professionals. The goal and learning objectives for the tutorial were included as part of the web-site (See appendix A). The tutorial began with a case example designed to capture the students' attention and illustrate how genetics is already playing a role in nutrition and healthcare (See appendix B). To receive full credit for the assignment,

students were required to accurately answer at least 70% of the questions that were interspersed throughout the tutorial (See appendix C). In addition, students were required to create a pedigree using either their own family history information or family history information from an anonymous friend (See appendix D). Links to more detailed information on a wide variety of topics were included throughout the tutorial. Although students were encouraged to browse these internal and external web pages it was not required as part of the tutorial, nor were the links necessary to provide correct answers for each question. (The tutorial is available at <http://www.genesoc.com/nutrition>)

#### IN-CLASS PRESENTATION

An hour-long in-class presentation on the genetics of diabetes mellitus (DM) was also developed and presented by the primary author. The presentation consisted of a PowerPoint lecture and group discussion of problem-based case scenarios (See appendices E & F). Case scenarios encouraged students to relate the genetic skills and knowledge they obtained from the tutorial and lecture to practical situations they may encounter in their future careers. To aid in answering the case questions students were given a handout summarizing the genetics of type 1 DM, type 2 DM, gestational DM, and other rarer forms of DM that result from a single inherited predisposing gene (See appendix G).

#### KNOWLEDGE

Pre and post-tests were used to assess the students' gain in knowledge (See appendix H). Both tests consisted of the same 20 multiple choice and true/false

questions. Some questions were created by the primary author, and others were adapted with permission from a test used to assess genetic knowledge among nurses.<sup>22</sup> Test questions focused on basic genetic concepts, recognizing inheritance patterns, genetic and nutritional interactions, the genetics of diabetes mellitus, and clues that indicate a condition may have a significant genetic component.

#### LIKELIHOOD AND CONFIDENCE

The pre and post questionnaires included 12 close-ended statements regarding genetic related services (i.e. eliciting and recording genetic information when obtaining a family medical history, discussing the genetic basis of conditions with patients, etc). Participants were asked to rate these statements on a 5-point Likert-type scale indicating: 1) the likelihood that they would perform these services at some point during their career and, 2) their confidence in their ability to perform these services regardless of whether or not they felt they would be asked to do so (See appendix I).

#### ATTITUDES

To assess what genetic issues or topics would be most useful, the pre and post questionnaires asked students to rate the importance of 17 genetics topics to their future career using a 5-point Likert-type scale (See appendix J). In addition, the post-questionnaire contained 6 open-ended and 23 closed-ended questions (rated on a 5 point Likert-type scale) that were designed to evaluate the students' attitudes about various aspects of the educational intervention (See appendix K).

## OTHER VARIABLES MEASURED

Several demographic and educational background questions were included as part of the pre-questionnaire (See appendix L). On the post-questionnaire students were asked to indicate whether or not they had completed the web-based tutorial, how long the tutorial took, and whether time was spent browsing any of the other web pages.

## RELIABILITY AND VALIDITY

A number of the statements about genetic related services and genetic topics of importance were adapted from the 1998 HuGEM national survey of Allied Health Professions, which was reviewed and revised by a number of professionals in a variety of allied health specialties.<sup>10</sup> Questionnaires for this study were reviewed by several professionals and students in genetics, nursing, and nutrition. Based on their recommendations, changes were made to improve readability, ease of use, content validity, and applicability to students. Test questions were reviewed and modified by several genetics and nutrition professionals and genetic counseling students in order to make them understandable, unambiguous, accurate, and reflective of information covered in the educational intervention.

Materials from the web-based tutorial and class presentation were presented to a group of 12 dietetic interns at a metropolitan hospital in the Midwest. Following the presentation, interns were asked to fill out the test and questionnaires. They were also asked to comment on how improvements could be made. The evaluation tools and educational materials were then revised based on their results and feedback. Data obtained from this pilot population are not included as part of the study results.

Following the study, internal-consistency estimates of reliability were calculated for likelihood and confidence statements on both the pre and post questionnaires. All 12-item Cronbach's alphas were  $\geq .9150$ , confirming that both the likelihood and confidence ratings demonstrated high reliability.

## DATA COLLECTION AND ANALYSIS

Data from the pre-tests and post-tests as well as the pre-questionnaires and post-questionnaires were matched according to unique student identification numbers and then entered into a database by the first author. To ensure accuracy of data entry, the first author checked the entire database against the original data three weeks following the completion of data entry.

Data were analyzed using Microsoft Excel and SPSS for Windows 11.0. Counts with percentages were calculated for closed-ended questions. Answers for Likert-type questions were categorized into the following three groups: Group 1 = a rating of 1 or 2; Group 2 = a neutral rating of 3; and Group 3 = a rating of 4 or 5. Frequencies for these three categories were then determined.

Characteristics of the data were evaluated prior to analysis. Test scores, total likelihood scores, and total confidence scores were normally distributed for both classes, and equal variances could be assumed. Based on this information, parametric tests were performed on these data. Individualized items from the questionnaires were not normally distributed and nonparametric tests were therefore utilized for data analysis of these items. Results from statistical analyses performed to test our hypothesis were considered significant at a two-sided p-value  $< .05$ . For all other statistical tests, Bonferroni

corrections were used to determine the critical two-sided p-value, so as to reduce the chance of a type 1 error.

Fisher's exact tests were used to determine whether nursing and dietetic students differed with regard to reported education in genetics. To determine whether there appeared to be associations among demographic variables, test scores, and confidence ratings, Spearman's rank-order coefficients and nominal by interval measures of association were performed.

The 20-item tests were scored by assigning one point for each correct response, for a total of 20 possible points. Differences in pre-test and post-test mean knowledge scores were calculated using paired t-tests. An independent samples t-test was used to determine if test scores differed significantly between nursing and dietetic students. Independent samples t-tests were also used to determine if there were differences in pre-test and post-test scores between students who did and did not complete the tutorial, and for those students who did and did not complete the study.

Paired Wilcoxon signed rank tests were calculated to determine whether there were significant changes in student's likelihood and/or confidence ratings for the 12 genetic-related services following the intervention. Mann-Whitney U tests were performed to test for differences between nursing and dietetic students with regard to confidence and likelihood ratings. Mann-Whitney U tests were also used to determine whether participants who completed both the pre and post-questionnaires differed from those who only completed one or the other.

Information obtained from the open-ended questions were recorded exactly and coded by the authors into categorical themes that emerged following data collection. Categorical frequencies are reported as well as samples of students' comments.

## **Results**

### **DEMOGRAPHICS AND EDUCATIONAL BACKGROUND**

A total of 87 nursing students and 21 dietetic students completed portions of the pre-questionnaire and/or pre-test, for initial participation rates of 87% and 88% respectively. The respondents from the two classes differed significantly from each other with respect to current level of education and average age ( $p \leq .0001$ ) (Table 1). Consistent with expectations based on past enrollment in the two courses, the majority of nursing students (82%) were college sophomores and the majority of dietetic students (76%) were college seniors. The nursing students were younger than the dietetic students with median ages equal to 20 and 22 years respectively. The vast majority of respondents in both courses were female, which is consistent with the significant imbalance in gender stratification among the nursing and dietetics professions.

There were no significant differences between nursing and dietetic students with respect to any of the variables that assessed previous genetics education (Table 2). The percent of students who reported having genetics in high school biology (approximately 85%) and the percent of students reporting no formal education in genetics (approximately 34%) were very similar for both nursing and dietetic students. Although responses to other genetics education questions were somewhat disparate between the two groups, none were statistically significant ( $p=0.068$  to  $p=0.095$ ).

## KNOWLEDGE SCORES

Fifty-seven nursing students and 18 dietetic students completed both the pre-test and post-test, for retention rates of 66% and 86% respectively. Knowledge scores increased significantly for both groups ( $p \leq .0001$ ). The average percent increase in scores following the intervention was 33% for nursing students and 21% for dietetic students (Table 3). Nursing students showed a greater absolute increase in knowledge scores compared to dietetic students, but the percent relative improvement from pre-test to post-test was higher among dietetic students than nursing students (Table 3). Although there were no statistically significant differences in the absolute or relative improvement in test scores, the average pre-test and post-test scores were both significantly higher for dietetic students compared to nursing students (pre-test  $p = .005$ , post-test  $p = .002$ ).

Pre-test and post-test scores were available for 16 students who did not complete the tutorial, one of whom was a dietetic student and the other 15 nursing students. Comparisons were made between nursing students who did and those who did not complete the tutorial (Table 3). Pre-test scores for nursing students who did not complete the tutorial were higher than for those who completed the tutorial; however, the difference was not statistically significant ( $p = .280$ ). In contrast, post-test scores were significantly higher for nursing students who did complete the tutorial compared to those who did not complete the tutorial ( $p = .004$ ).

Average test scores tended to be higher for those students who were further along in their training and for students who reported having previous education in genetics. Students' level of educational training was positively correlated with both pre-test and post-test scores (pre-test  $r_s = .338$   $p \leq .0001$ , post-test  $r_s = .372$   $p \leq .001$ ). The following

genetics educational variables were modestly associated with higher test scores; having a bachelor's degree in biology (pre-test  $\eta=0.245$ , post-test  $\eta=0.475$ ), having genetics in one or more undergraduate courses (pre-test  $\eta=0.238$ , post-test  $\eta=0.323$ ), and having genetics as part of high school biology (pre-test  $\eta=0.243$ ).

## CONFIDENCE AND LIKELIHOOD RATINGS

Prior to the intervention, 85 nursing students (85%) and 21 dietetic students (88%) rated 12 statements regarding genetic related services for both the likelihood that they would perform these services and their confidence in their ability to perform these services. Of these, 61 nursing students and 18 dietetic students also rated these same statements following the intervention (retention rates = 72% and 86% respectively).

Total likelihood and confidence scores did not differ between nursing students and dietetic students before or after the intervention ( $p=.466$  to  $p=.713$ ) (Table 5). Single-item ratings were also not statistically different between the two groups when using the Bonferroni correction for multiple tests ( $p<0.002$ ) (Table 6). Based on these results, data for both nursing and dietetic students are reported together.

Students' likelihood ratings were higher than their confidence ratings for all of the 12 genetic related services on a 5 point Likert-type scale (Table 6). Prior to the intervention, median likelihood ratings for six of the twelve statements were 4s (likely), one was a 3.5, and five were 3s. In contrast to this, only two out of the twelve genetic related services received median confidence ratings of 4, while seven received median ratings of 3 and two received ratings of 2 (low confidence).

Although the majority of students felt that they would likely or very likely perform all 12 genetic related services, their average total confidence rating for these services prior to the intervention was just below 2.9 on a 5 point Likert-type scale. This indicates that the majority of students lacked confidence in their ability to perform genetic related services. However, following the intervention the average total confidence rating increased significantly to 3.5 ( $p < .05$ ).

Following the intervention the average total likelihood ratings and average total confidence ratings increased significantly ( $p < .05$ ) (Table 5). However, when ratings were analyzed separately for the likelihood of performing each genetic related service, the increase was only significant for the likelihood that students would identify patients who would benefit from genetic counseling and the likelihood students would make appropriate referrals for genetic counseling ( $p \leq .001$ ). In contrast, the increase in confidence ratings was significant for ten of the twelve genetic related services ( $p \leq 0.002$ ). Although confidence ratings for the other two genetic-related services increased, the increases were not significant after using the Bonferroni correction for multiple tests ( $p = 0.008$  and  $p = 0.187$ ).

Students' present level of educational training and previous education in genetics were not correlated with their confidence ratings. Confidence ratings were not significantly correlated with test scores either.

#### ATTITUDES ABOUT GENETIC TOPICS OF IMPORTANCE

Eighty-five nursing students (85%) and 21 dietetic students (87.5%) rated the importance of 17 genetics topics prior to the intervention. Following the intervention, 77

nursing and 21 dietetic students rated the importance of these same topics. Of the follow-up responders, 15 nursing students and 3 dietetic students had not completed the pre-questionnaire. Therefore retention rates for this portion of the study were 73% for nursing students and 86% for dietetic students.

Following the intervention, no significant changes in importance ratings of the 17 topics were found ( $p=0.074$  to  $p=.831$ ). Median ratings indicated that nearly all of the topics were either very important (5) or somewhat important (4) by over 50% of dietetic and nursing students. Median ratings from nursing students on all 17 topics both before and after the intervention were equal to 4 or 5. Although the median ratings for the dietetic students were mostly 4s and 5s, three topics received median ratings of 3 prior to the intervention. These three topics included 1) the genetic counseling process, 2) identifying patients who would benefit from genetic counseling or genetic testing, and 3) ethical, legal, and social implications of genetic testing. Following the intervention only the genetic counseling process maintained a median rating of 3 by the dietetic students.

Both dietetic and nursing students listed genetics of common diseases and metabolic disorders in the top 5 topics of importance (based on average ratings) before and after the intervention (Table 7). Privacy and confidentiality in releasing genetic information was among the top 5 topics of interest among nursing students and it moved up from 7<sup>th</sup> to 5<sup>th</sup> in the dietetic rankings following the intervention. For nursing students genetically modified foods was rated as least important before and after the intervention, while it remained in the top five for dietetic students. The genetic counseling process was rated among the three least important topics for both groups before and after the intervention.

## ATTITUDES ABOUT ASPECTS OF THE EDUCATIONAL INTERVENTION

Seventy-four nursing students and 21 dietetic students completed evaluation forms rating their satisfaction with the educational strategies that were used in this study to incorporate genetics into the curricula (Tables 8-11). The majority of students agreed or strongly agreed with most of the 23 positively worded statements regarding various aspects of the educational intervention (1=strongly agree, 5=strongly disagree). Among nursing students, median ratings for 4 of the 23 positively worded statements were 1's (strongly agree), 14 statements received median ratings of 2 (agree), while the remaining 5 received a median rating of 3 (neutral). Among dietetic students, median ratings for 17 of the 23 statements were 1's, one statement received a median rating of 1.5, four statements were given 2's, and one statement received a median rating of 2.5.

The majority of respondents in both disciplines agreed that genetics is an important subject for their future career and should be integrated into multiple courses. Approximately two-thirds of dietetic students agreed that the course was an ideal place to incorporate genetics, while just under half of the nursing students agreed with this statement (Table 8).

Of the 20 dietetic and 64 nursing students who reported completing the web-based tutorial, the majority agreed with the following two statements; 1) "the tutorial was an enjoyable way to learn genetics" and 2) "the tutorial helped me appreciate the relevance of genetics to my future career". Over 66% of nursing students and approximately 95% of dietetic students reported that the tutorial was both easy to use and written at a level they could understand. Dietetic students were more likely than nursing students to agree

that the web-based tutorial made the genetic information interesting, helped them understand principles of basic genetics, and helped them apply the genetic information to real-life situations (Table 9).

When asked what they enjoyed most about the tutorial, 11 students indicated that they liked the new information they learned or the specific content that was included, 10 students indicated that the pedigree was most enjoyable, 9 indicated that the tutorial was interesting, 7 stated it was easy to use, another 7 commented on how it was easy to understand, 7 reported that it was educational or informative, 7 indicated the pictures were most enjoyable, 4 enjoyed the links, 3 liked having practice questions interspersed throughout the tutorial, and 1 liked having a link to the answers at the end of the tutorial for immediate feedback.

When asked what was least enjoyable about the tutorial, 28 students commented on the length of time it took to complete. Students had been told that it would take approximately 45 minutes, but that this was highly dependent on how much they already knew about genetics and on how many links they chose to review. The average length of time it took students to complete the tutorial was 57 minutes; however, this was highly variable with a minimum time to completion of 15 minutes and a maximum of 130 minutes (Table 12). Although students were not required to visit links to other web-pages as part of the assignment, most of the students who commented about how the tutorial took a lot of time were among the 68% who reported that some of their time was spent visiting outside links. (Table 13).

Over 70% of respondents in both groups felt the class presentation was enjoyable and an effective method for learning genetics (Table 10). In response to questions

concerning the use of case scenarios, 84-89% of dietetic students agreed that the scenarios were enjoyable, interesting and an effective method for learning genetics, whereas only 66-77% of nursing students agreed with these statements. Greater than 69% of both dietetic and nursing students agreed the case scenarios helped them understand basic genetic principles, apply genetics to real-life situations and appreciate the relevance of genetics to their future career (Table 11).

Written comments about the in-class presentation were as follows; 31 students found the case studies enjoyable, 14 indicated the amount or type of information learned was most enjoyable, 12 stated that it was interesting, 9 indicated that the content was relevant or applicable to their career or real-life situations, 7 positively regarded attributes of the speaker and or clarity of the presentation, 3 indicated that working in groups was most enjoyable, and 3 indicated their appreciation of the extra credit or food coupon that were offered as incentives.

When asked what was least enjoyable about the presentation, 9 students indicated that everything was enjoyable, 8 stated the presentation length, 7 identified the lecture portion of the presentation, 6 listed the amount of presented information, 4 indicated repetitious parts of the presentation, 4 commented on how they would have liked more diseases other than diabetes to be covered, and 2 indicated that the quiz was least enjoyable.

#### COMPARISON OF PARTICIPANTS BASED ON COMPLETION OF THE STUDY

All students enrolled in the medical nutrition therapy course and all but one nursing student participated in at least the pre-intervention or post-intervention evaluation

components of this study. Only small differences were found in pre-test and post-test scores among participants who did and did not complete both tests and those who did and did not complete both questionnaires ( $p=.323$  to  $p=.865$ ). There were also no statistically significant differences with regard to present level of training, age, total likelihood ratings, and total confidence ratings between students who completed both questionnaires and those who did not ( $p=.258$  to  $p=.950$ ).

## **Discussion**

### **GENETICS KNOWLEDGE**

Increases in test scores following the intervention were similar for both dietetic and nursing students, despite differences in the present level of training between these two groups. Although dietetic students' absolute gain in knowledge was slightly lower than that of nursing students, this is likely explained by the fact that dietetic students began with significantly higher pretest scores and therefore had less room for improvement than the nursing students. Support for this explanation comes from data showing that the relative percent improvement for dietetic students was higher than for nursing students.

There are a number of reasons why dietetic students may have scored higher on both the pretest and posttest. One likely explanation is that the dietetic students are farther along in their training than the nursing students. The positive correlation between students' level of educational training and their test scores supports this explanation. This being the case, dietetic students may have accrued more knowledge of genetics and/or they may have better test taking abilities. Another possible explanation is that,

since the nursing course is designed for sophomores, there has been little time for the attrition of students who do not perform as well in an academic setting.

Since nursing students were not as far along in their training, it was not surprising that the pre-test average for the nursing class (56%) was lower than the average for the dietetic students (72%), who were mostly seniors. What was surprising however was to examine which questions were frequently missed. For example, when asked which of the following is/are true about the role of DNA, only 39% of nursing students and 48% of dietetic students provided the correct response. Admittedly this is somewhat concerning; however, following the intervention 71.4% of nursing students and 95% of dietetic students correctly answered this question. Before the intervention most students missed the two questions about genetic risks associated with type 1 and type 2 diabetes mellitus. On the pretest only 10% of nursing students and 19% of dietetic students correctly answered the question about the roles of genetic counselors. The majority of individuals indicated that one of the roles of a genetic counselor is to “advise individuals on whether or not they should have children based on their family history.” This could indicate that students incorrectly believe eugenics is the underlying ethos of genetic counseling, or at the very least it provides some indication that students in allied health lack a clear understanding of the primarily non-directive approach of genetic counseling when providing services. Such misinformation could hinder them from making appropriate referrals, which is one of the minimum competencies recommended for all health care professionals by the National Coalition for Health Professional Education in Genetics.<sup>2</sup> Following the brief educational intervention, the percentage of students who could

correctly recognize roles performed by a genetic counselor increased to 39% for the nursing students and over 50% among the dietetic students.

Since instructors were not aware of what students already knew about genetics, it was interesting to discover which questions most students answered correctly prior to the intervention. Based on pre-test answers to true/false questions, over 80% of all students were aware that “genetic testing is available to determine if an individual is at an increased risk for certain common diseases including heart disease, breast cancer and colon cancer.” Over 90% were aware that “genetic test results have the potential to reveal information about the genetic status of an individual’s family members” and that “some genetic disorders are more commonly found in people of specific ethnic backgrounds.” The multiple choice question designed to assess students’ knowledge about folic acid and the prevention of birth defects was answered correctly on the pretest by over 80% of the nursing students and by 100% of the dietetic students.

#### CONFIDENCE IN PERFORMING GENETIC RELATED SERVICES

Despite nursing and dietetic students’ general lack of confidence prior to the intervention, they were more likely than respondents from the 1998 HuGEM survey of allied health professionals to indicate confidence (rating of 4 or 5) in performing a number of genetic related services.<sup>10</sup> The HuGEM survey was mailed to 600 randomly selected members of national professional organizations in the following six disciplines; dietetics, physical therapy, psychology, social work, occupational therapy, and speech pathology/audiology. Response rates ranged from 47% for psychologists to 62% for dietitians and 64% for speech pathologists/audiologists.

Only 16.1% of HuGEM survey respondents reported having confidence in their ability to discuss the genetic basis of disorders/conditions with their clients, whereas 40.4% of the nursing and dietetic students that participated in this study were confident in their ability to perform this service even before the educational intervention. This may be an indicator of their misunderstanding about what is entailed in discussing the genetic basis of conditions. The HuGEM survey found that 21% of respondents were confident in their ability to elicit and record genetic information, while the present study found that 38.1% of study participants were confident in their ability to perform this task. Only 16% of HuGEM respondents reported confidence in their ability to provide guidance to clients with genetic disorders about what impact the genetic condition may have for their clients' future, whereas 23.8% of the study participants in the present study were confident in performing this role. The HuGEM survey found that only 19.7% of health care professionals were confident in making referrals for genetic counseling, which was not much different from the results of the present study. Prior to the intervention only 22.8% of these dietetic and nursing students were confident in making referrals for genetic counseling; however this increased to 53.6% after the students completed the intervention. It is difficult to interpret why the students might be more confident in performing these genetic services when they have not yet had an opportunity to practice them. However, it may have to do with the fact that the students reported having more education in genetics than was reported by respondents to the HuGEM survey. It may also be due to the fact that neither group of students had participated in clinical rotations where they had the opportunity to provide patient education. Therefore, their responses were based on theoretical rather than practical knowledge.

Services for which nursing and dietetic students reported having lower confidence than the HuGEM survey respondents included: obtaining written informed consent to release genetic information to third parties (24.3% of HuGEM respondents and 14.1% of students were confident), making referrals for psychological counseling related to genetic issues (35.7% of HuGEM participants reported confidence compared to 29.5% of students), and providing psychological counseling related to coping with a newly diagnosed genetic disorder or test result (20.2% compared to 17.2%).

Confidence ratings were significantly higher for those participants in the HuGEM survey who reported more formal education in genetics. Our study however found no correlations between confidence ratings and amount of formal education in genetics.

Significant increases in confidence were found for all students who were present for the in-class presentation regardless of whether or not they had previously completed the tutorial. This is not surprising given that completing case-based problems has previously been shown to increase physicians' confidence in clinic-related skills<sup>52</sup> and case-based instruction was better than lectures at increasing confidence among high school students who were studying genetics.<sup>66</sup>

#### ATTITUDES REGARDING GENETIC TOPICS OF INTEREST

The genetic topic rated most important by dietetic and nursing students in this study was the genetics of common diseases (i.e. heart disease, diabetes, etc.). This is also the topic that was rated as being most useful by allied health professionals in the HuGEM study.<sup>10</sup> Privacy and confidentiality in releasing genetic information was also rated among the top 7 topics in both the HuGEM study and the present study. Helping patients

cope with a genetic diagnosis was in the top 4 most useful topics in the HuGEM study and was ranked among the top 7 topics of importance by nursing students, but was ranked lower by dietetic students. Many of the genetics topics that were reported as being most important by dietetic students in this study were not included in the 1998 HuGEM study, probably because they were specific to nutrition. Examples of such topics include: gene-diet interactions, genetically modified foods, and genetic influences on nutrition requirements. Overall, both the HuGEM study and our study found that nearly all of the genetic related topics were considered at least somewhat important or useful to the majority of participants.

#### ATTITUDES ABOUT THE EDUCATIONAL STRATEGIES

Our data demonstrate that students perceived case-based learning more positively than the web-based tutorial. However, this does not mean the tutorial was ineffective. The importance of the tutorial in increasing genetics knowledge is illustrated by the finding that nursing students who failed to complete the tutorial did not experience a significant increase in knowledge, while those nursing students who did complete the tutorial showed a significant increase in test scores following the intervention. The lack of a significant difference between their initial test scores supports the idea that the basic knowledge obtained in the tutorial was a critical part of the intervention. However, because this conclusion is based on serendipitous findings there could be another explanation that was not controlled for in the study design.

On open-ended questions, 7 students commented that the least enjoyable part of the presentation was the lecture portion, 8 reported that the presentation was long, and 6

stated that too much information was included in the presentation. Despite these negative comments, over 70% of the students felt the presentation was both an effective and an enjoyable method for learning genetics. Uncertainty remains as to whether these positive comments were more reflective of the lecture or the case-based instruction since students were not asked questions specific only to the lecture. However, responses to questions specific to the use of case-based instruction were positive. Consistent with findings from previous research,<sup>46;47;56-60</sup> the majority of nursing and dietetic students in this study indicated that solving case-based problems helped them apply the information they learned to real-life situations and they agreed it was an effective and an enjoyable method for learning genetics.

#### INCORPORATING GENETICS INTO ALLIED HEALTH CURRICULA

Genetics is emerging as a topic of importance in health care, and data from our study support the idea that nursing and dietetic students believe that genetics will play an important role in their future career. Despite its importance, integrating genetics into an already packed curriculum can be a challenge and may be perceived as a burden by both faculty and students. A number of students in our study recognize this additional burden and indicated on open-ended questions that they already have too much to worry about, that a genetics course should be offered as an elective, or that it took too much of their time.

Only a handful of students in this study suggested on the open-ended questions that an entire course in genetics should be added to the required curricula, while a slightly larger number of students commented on how genetics should be included in more

lectures and/or courses. Over half of the nursing students and greater than two-thirds of the dietetic students agreed or strongly agreed with the closed-ended question that genetics should be integrated into multiple courses. Based on these results, it seems that including genetics in multiple pre-existing courses is acceptable to students and this approach may be more feasible than creating an entire course on genetics.

Integrating genetics into multiple courses presents some challenges. One challenge encountered by the authors was that faculty members lacked a complete understanding of what their students already knew about genetics. Another challenge was that a number of faculty members were concerned about diverting time from other required course subjects. A third challenge was that faculty members believed genetic topics fit better or were already included in other courses within the curricula. These challenges could potentially be reduced if the program curriculum were thoroughly reviewed in order to determine what genetics concepts are taught in which courses and make certain that important topics were not inadvertently omitted from the curricula.

Although this study included genetics content in only a single course within the nursing and dietetic curricula, it may be more beneficial to incorporate genetics into multiple courses for two main reasons; 1) dividing the genetics content among different courses means that less time is taken away from other critical topics that are already part of each course, and 2) genetics knowledge will be reinforced throughout the students training, thereby making it more likely that students will remember genetic concepts and recognize how genetics relates to multiple situations within their clinical practice. Ideally genetics would be integrated into the curriculum early on in the program, followed by the inclusion of genetics content in multiple courses. The tutorial could provide students

with the basic knowledge of genetics early on and could also serve as a reference throughout the program curricula.

Despite the potential benefits of integrating genetics into multiple courses, concern remains about whether a small amount of genetic information, scattered throughout the curriculum, will effectively increase students' knowledge and skills in genetics. Results from the present study demonstrate that incorporating a short-term genetics educational intervention into a single existing course was enough to significantly improve nursing and dietetic students' knowledge of genetics and their confidence in their ability to perform genetic related services. However, since only short-term measurements of knowledge and confidence were obtained it is likely that the increases in both knowledge and confidence will fade over time. This diminishing of knowledge may be averted through multiple exposures to genetics content throughout the curriculum.

#### STUDY LIMITATIONS AND STRENGTHS

As mentioned previously, the present study did not measure long-term gains in knowledge or confidence. Another study limitation is that the tests may have been somewhat reflective of students' test taking abilities rather than their actual knowledge. This is particularly concerning for the 9 true/false questions because there is a higher chance of guessing the correct answer from two choices than there is for the multiple choice questions which had five possible choices.

Other study limitations result from the potential bias that can occur with the lack of a true experimental design. Without a control group and random assignment, it is

uncertain whether events other than the educational intervention could have contributed to the observed increase in students' knowledge and/or confidence.

Student ratings on the post-questionnaires could have been biased by exposure to the pre-intervention assessment tools or by the "halo effect," which results when participants report answers that reflect what is anticipated or expected in the study.

Increases in knowledge scores are not as likely as student ratings to be attributed to outside influences for the following reasons; 1) tests are more objective than measures of confidence, 2) answers to test questions were not provided until after the study was completed, and 3) the study found that nursing students who did not complete the tutorial scored significantly lower on the posttest (but not the pretest) when compared to students who did complete the tutorial. Test scores are therefore likely to be a less biased construct for measuring change than confidence ratings.

One of the strengths of this study was that both knowledge and confidence were measured and both showed a significant increase following the intervention. The study's major strength however is that response bias is minimal based on the findings that a representative and large sample from both courses participated in and completed the study.

## APPLICATIONS AND FUTURE DIRECTIONS

Because this intervention was successful in nutrition courses for two different health care specialties, it is likely that these educational materials would also be effective in other training programs that offer nutrition courses. Research has shown that the more personalized the educational intervention, the more effective it is.<sup>44</sup> Therefore, one of the

reasons for the success of this intervention is likely due to its relevance to nutrition and applicability to clinical health care practice.

Although designed specifically for nutrition related courses, this type of intervention could be successful in other allied health disciplines. However, to achieve success revisions would need to be made to the examples contained in the tutorial and new case studies should be created so that the intervention is relevant to topics that will likely be encountered in each specific allied health discipline.

Future research may be geared toward determining the effectiveness of genetics educational interventions in a variety of other allied health training programs. Other research studies are also needed to determine whether incorporating genetics into multiple courses throughout the curriculum is more beneficial at increasing and maintaining genetics knowledge and confidence than creating a separate course in genetics.

Integrating genetics into the allied health curricula is an essential step in preparing allied health professionals for the impact that the genetics revolution is expected to have on the practice of health care. Results from this study indicate that a multifaceted approach to delivering genetics content in a nutrition course is one effective approach for preparing future healthcare professionals for the genetics revolution

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## Tables

**Table 1. Demographics of participants in the two courses**

Variable	Nursing Class <i>n</i> =85	Dietetics Class <i>n</i> =21
<b>*Level of current training (% of students)</b>		
College sophomore	82.4%	0%
College junior	8.2%	9.5%
College senior	1.2%	76.2%
Graduate school	5.9%	9.5%
Other	2.4%	4.8%
<b>Gender (% of students)</b>		
Male	10.6%	14.3%
Female	89.4%	85.7%
<b>*Age (years)</b>		
Mean	21.9	26.7
Median	20	22

\* Significant difference between nursing and dietetic students (Mann-Whitney U tests,  $p \leq .0001$ )

**Table 2. Percent of students who responded yes to statements regarding previous genetics education**

Statement	Nursing <i>n</i> =85	Dietetics <i>n</i> =21	* <i>p</i> -value
Genetics in high school biology	83.5%	85.7%	1.00
Genetics class in high school	5.9%	19.0%	.074
Genetics as part of an undergraduate course(s)	63.5%	85.7%	.068
College course on genetics	10.6%	4.8%	.683
Bachelor's degree in biology	8.2%	14.3%	.411
Bachelor's degree in genetics	0%	0%	--
No formal genetics education	34.1%	33.3%	1.00
I attended a seminar/workshop on genetics	3.6%	14.3%	.095

\* Two-sided Fisher's exact tests indicate that there were no significant differences between nursing and dietetic students with regard to previous genetics education

**Table 3. Average test scores  $\pm$  SD, percent change in scores following the intervention, and relative % improvement**

Group	<i>n</i>	Pre-test	Post-test	<sup>a</sup> <i>p</i> -value	% change	relative % improve
All students	75	11.8 $\pm$ 2.8	14.7 $\pm$ 2.9	<.0001*	30.2%	33.0%
By class						
Nursing students	57	11.3 $\pm$ 2.8	14.2 $\pm$ 2.9	<.0001*	33.1%	30.7%
Dietetic students	18	14.3 $\pm$ 1.9	16.1 $\pm$ 2.5	<.0001*	21.3%	40.5%
Tutorial (nursing only)						
Completed	39	11.2 $\pm$ 3.1	<sup>†</sup> 14.8 $\pm$ 2.7	<.0001*	35.4%	37.4%
NOT completed	15	11.6 $\pm$ 2.0	<sup>†</sup> 12.4 $\pm$ 2.7	0.280	9.2%	7.6%

<sup>a</sup>paired t-test

\*Statistically significant increases ( $p < .05$ )

<sup>†</sup>Post-test scores were significantly higher for nursing students who reported completing the tutorial compared to nursing students who did not ( $p = .004$ ).

**Table 4. Change in average total likelihood and average total confidence ratings**

Group	<i>n</i>	Likelihood Ratings 1 = NOT likely 5 = VERY likely			Confidence Ratings 1 = LOW 5 = HIGH			
		<sup>a</sup> before	<sup>a</sup> after	<sup>b</sup> <i>p</i> -value	<i>n</i>	<sup>a</sup> before	<sup>a</sup> after	<sup>b</sup> <i>p</i> -value
All students	78	3.42 $\pm$ .84	3.72 $\pm$ .69	*.002	76	2.85 $\pm$ .93	3.49 $\pm$ .70	* $\leq$ .0001
By class								
Nursing	61	3.51 $\pm$ .77	3.75 $\pm$ .66	*.014	58	2.88 $\pm$ .95	3.47 $\pm$ .69	* $\leq$ .0001
Dietetics	17	3.11 $\pm$ 1.0	3.62 $\pm$ .80	.056	18	2.75 $\pm$ .88	3.56 $\pm$ .74	*.002
Tutorial (nursing only)								
Completed	42	3.43 $\pm$ .75	3.72 $\pm$ .65	*.022	40	2.85 $\pm$ .86	3.50 $\pm$ .60	* $\leq$ .0001
NOT completed	16	3.69 $\pm$ .79	3.86 $\pm$ .71	.382	15	2.98 $\pm$ 1.2	3.41 $\pm$ .83	*.021

<sup>a</sup>total mean ratings for the 12 genetic related services  $\pm$  SD

<sup>b</sup>paired t-tests

\*statistically significant increase ( $p < .05$ )

**Table 5. Change in likelihood and confidence ratings for each of the 12 genetic related services**

Genetic related service	Likelihood Ratings 1 = NOT likely 5 = VERY likely			Confidence Ratings 1 = LOW 5 = HIGH		
	<sup>a</sup> before	<sup>a</sup> after	<sup>b</sup> <i>p</i> -value	<sup>a</sup> before	<sup>a</sup> after	<sup>b</sup> <i>p</i> -value
	<i>n</i> 79-80	<i>n</i> 78-79		<i>n</i> 79-80	<i>n</i> 78-79	
1. Elicit and record genetic information when eliciting family medical history	4	4	.038	3	4	.001*
2. Discuss the genetic basis of disorders/conditions with patients	4	4	.252	3	4	.001*
3. Discuss your patients' genetic risks for common diseases such as diabetes and heart disease	4	4	.849	4	4	.008
4. Correct misconceptions about genetic disorders	3.5	4	.073	3	3	<.0001*
5. Identify patients who would benefit from genetic counseling	4	4	.001*	3	4	<.0001*
6. Make appropriate referrals for genetic counseling	3	4	<.0001*	3	4	<.0001*
7. Make referrals for psychological counseling related to genetic issues	3	4	.135	3	3	<.0001*
8. Provide guidance to patients with genetic disorders about the impact a genetic condition may have	4	4	.085	3	3	<.0001*
9. Provide counseling to patients making decisions about whether to have genetic testing	3	4	.032	2	3	<.0001*
10. Provide psychological counseling related to coping with a newly diagnosed genetic disorder	3	3	.097	2	3	<.0001*
11. Obtain written informed consent to release genetic information to third parties	3	3	.482	3	3	.002*
12. Find and understand literature on genetic/nutrition related research	4	4	.547	4	4	.187

<sup>a</sup>Median ratings are shown

<sup>b</sup>Wilcoxon signed rank tests

\*Statistically significant increase ( $p \leq 0.002$ )

**Table 6. Top 5 most important genetics topics before and after the intervention**

rank	Nursing Class		Dietetics Class	
	before <i>n</i> =85	after <i>n</i> =77	before <i>n</i> =21	after <i>n</i> =21
1)	Genetics of common diseases (4.42)	Genetics of common diseases (4.26)	Genetics of common diseases (4.62)	Metabolic disorders (4.85)
2)	Importance of family history in estimating the likelihood that a person will develop a disease (4.41)	Privacy and confidentiality in releasing genetic information (4.22)	*Metabolic disorders (4.57) *Identifying other family members who may benefit from dietary interventions (4.57)	Identifying other family members who may benefit from dietary interventions (4.81)
3)	Privacy and confidentiality in releasing genetic information (4.40)	Importance of family history in estimating the likelihood that a person will develop a disease (4.18)	Genetic influences on nutrition requirements (4.52)	*Genetic influences on nutrition requirements (4.76) *Gene-diet interactions (4.76)
4)	Helping patients cope with a genetic diagnosis (4.31)	Inheritance patterns (4.17)	Genetically modified foods (4.48)	*Genetically modified foods (4.67) *Genetics of common diseases (4.67)
5)	Metabolic disorders (4.28)	Metabolic disorders (4.14)	Gene-diet interactions	Privacy and confidentiality in releasing genetic information

\*Indicates topics for which mean scores were tied.

**Table 7. Evaluation: Incorporating genetics into the curricula**

Statement	% of nursing students (n=75 to 76)			% of dietetic students (n=21)		
	<sup>a</sup> A	<sup>b</sup> N	<sup>c</sup> D	<sup>a</sup> A	<sup>b</sup> N	<sup>c</sup> D
This course was an ideal place to incorporate genetics topics	47.4%	44.7%	7.9%	66.7%	28.5%	4.8%
Genetics is a valuable/important subject for my future career	67.1%	30.3%	2.6%	71.4%	23.8%	4.8%
Genetics should be integrated into multiple courses	50.7%	38.7%	10.7%	76.2%	23.8%	0%
Because of this class, I am interested in learning more about genetics	37.3%	41.3%	21.3%	66.7%	23.8%	9.5%

<sup>a</sup>A =agree (rating of 1 or 2), <sup>b</sup>N =neutral (rating of 3), <sup>c</sup>D =disagree (rating of 4 or 5)

**Table 8. Evaluation: Web-based tutorial**

Statement	% of nursing students (n=52 to 54)			% of dietetic students (n=19 to 20)		
	<sup>a</sup> A	<sup>b</sup> N	<sup>c</sup> D	<sup>a</sup> A	<sup>b</sup> N	<sup>c</sup> D
Helped me see the relevance of genetics to my future career	53.7%	33.3%	13.0%	50.0%	40.0%	10.0%
Made the genetic information interesting	49.1%	41.5%	9.4%	70.0%	20.0%	10.0%
Helped me understand principles of basic genetics	53.8%	4.6%	11.5%	90.0%	5.0%	5.0%
Is an enjoyable way to learn genetics	52.8%	34.0%	13.2%	55.0%	40.0%	5.0%
Helped me apply the genetic information to real-life situations	48.1%	38.5%	13.5%	80.0%	15.0%	5.0%
Was written at a level that I could understand	67.9%	24.5%	7.5%	94.7%	5.3%	0%
Was easy to use	64.2%	28.3%	7.5%	95.0%	5.0%	0%

<sup>a</sup>A =agree (rating of 1 or 2), <sup>b</sup>N =neutral (rating of 3), <sup>c</sup>D =disagree (rating of 4 or 5)

**Table 9. Evaluation: Class presentation**

Statement	% of nursing students (n=73)			% of dietetic students (n=19)		
	<sup>a</sup> A	<sup>b</sup> N	<sup>c</sup> D	<sup>a</sup> A	<sup>b</sup> N	<sup>c</sup> D
The presentation was enjoyable	71.2%	16.4%	12.3%	84.2%	5.8%	0%
The presentation was well organized	89.0%	4.1%	4.1%	94.7%	5.3%	0%
The speaker was knowledgeable about the subject of genetics	83.6%	9.6%	6.8%	84.2%	15.8%	0%
The speaker was clear and easy to understand	84.9%	6.8%	8.2%	94.7%	5.3%	0%
The presentation was an effective method for learning genetics	71.2%	16.4%	12.3%	94.7%	5.3%	0%

<sup>a</sup>A =agree (rating of 1 or 2), <sup>b</sup>N =neutral (rating of 3), <sup>c</sup>D =disagree (rating of 4 or 5)

**Table 10. Evaluation: Case scenarios**

Statement	% of nursing students (n=73)			% of dietetic students (n=19)		
	<sup>a</sup> A	<sup>b</sup> N	<sup>c</sup> D	<sup>a</sup> A	<sup>b</sup> N	<sup>c</sup> D
Helped me see the relevance of genetics to my future career	69.9%	23.3%	6.8%	73.7%	21.1%	5.3%
Made the genetic info interesting	65.8%	27.4%	6.8%	89.5%	10.5%	0%
Helped me understand principles of basic genetics	67.1%	23.3%	9.6%	84.2%	15.8%	0%
Is enjoyable way to learn genetics	68.5%	24.7%	6.8%	84.2%	15.8%	0%
Helped me apply the genetic information to real-life situations	74.0%	16.4%	9.6%	89.5%	10.5%	0%
Were written and presented at a level that I could understand	80.8%	13.7%	5.5%	94.7%	5.3%	0%
Was an effective method for learning genetics	76.7%	16.4%	6.9%	84.2%	15.8%	0%

<sup>a</sup>A =agree (rating of 1 or 2), <sup>b</sup>N =neutral (rating of 3), <sup>c</sup>D =disagree (rating of 4 or 5)

## **Appendix A: Goal and Learning Objectives for the Web-Based Tutorial Assignment**

### **Overview: What is your assignment?**

Review the following tutorial and answer all of the questions included throughout the four short sections:

1. The Role of Genetics in Your Profession (4 questions)
2. Eliciting Genetic Health Risks (1 question and family medical pedigree)
3. Basic Genetics Review (2 questions)
4. Interpreting Genetic Health Risks (10 questions)

The tutorial should take approximately 45 minutes to complete. You must answer all of the questions and score 70% or higher to receive full credit for the assignment. Please write your answers on the answer sheet provided in class. If you do not have an answer sheet one can be obtained by clicking on the following link [answer sheet](#).

Links to other websites can be found throughout the tutorial. These links will provide you with further information about selected topics. It is not required that you visit all of the outside websites, but you may find them interesting and/or helpful in answering some of the questions.

### **Goal:**

Following this assignment you will recognize how genetics may impact your future career and you will have confidence in your ability to find, utilize and understand genetic information and resources.

### **Learning Objectives: What will I be able to do?**

1. Demonstrate the ability to think critically about how the field of genetics may influence your future profession
2. Obtain and record genetic information while taking a family medical history
3. Understand basic genetic principles
4. Recognize various inheritance patterns and the genetic risks for each pattern

### **Procedure: How do I begin?**

To start the assignment click on the link below. Be sure you are using internet explorer or you will be unable to access this tutorial.

## **Appendix B: Case example from the beginning of the tutorial**

A client/patient comes to you and wants you to order a genetic test she read about on the internet called "*Body Benefits - nutrition*"

### **What would you do?**

rhetorical question – no answer required

The company that offers this test claims that, "small differences in your genes can influence how well your body metabolizes foods, utilizes nutrients and excretes damaging toxins, all of which can affect your general state of health. By finding out if you have any of these small variations, Body Benefits - nutrition can provide you with specific dietary information that cannot be obtained from any other source."

### **What do you think of the company's claim?**

rhetorical question

The company that markets "*Body Benefits - nutrition*" is located in the UK and their website is [www.sciona.com](http://www.sciona.com)

- Direct marketing to the public stopped in July of 2002
- This test is now available to the public only through a health care professional
- American companies are already marketing similar genetic tests that determine susceptibility to diseases influenced by both genetic and dietary factors [www.genovations.com](http://www.genovations.com)  
[www.myriad.com/med/cardiarisk/index.html](http://www.myriad.com/med/cardiarisk/index.html)

## Appendix C: Tutorial Questions and Answers

### *Part I*

There are a number of potential answers to the questions in part one, all of which pertain to the case example presented at the beginning of the tutorial. The following is a list of only some of the possible answers.

#### **1. Questions this type of genetic testing raises**

- ❑ Should I order the testing?
- ❑ Who is interpreting the results and how accurate are they?
- ❑ Would I feel confident in counseling an individual about what their results mean?
- ❑ Is the dietary advice provided different than advice that I already provide or than I could provide based on a family medical history?
- ❑ Is this worth the money that an individual would have to pay?
- ❑ How much does our genetic make-up really impact health and disease?

#### **2. Benefits or reasons this type of genetic testing might be supported**

- ❑ May potentially be a strong catalyst to prompt dietary and lifestyle changes that could prevent disease
- ❑ Individuals have the right to know about their genetic risks
- ❑ This may be the first step to providing individualized dietary recommendations based on an individual's genes

#### **3. Concerns this testing raises**

- ❑ Could imply that genes are more important than other factors in disease
- ❑ Certain variations in these genes may increase risk for some diseases with a dietary and lifestyle component, but their role in disease is not completely understood
- ❑ It is still unclear how much influence these genes really have on health and disease
- ❑ Potential for a false sense of security
- ❑ Potential for a fatalistic attitude
- ❑ Raises confidentiality and insurability issues

#### **4. Diseases that are influenced by both genes and nutrition (these are only a few)**

- ❑ Diabetes
- ❑ Heart Disease
- ❑ Hypertension
- ❑ Spina Bifida
- ❑ PKU

- ❑ Cystic fibrosis
  - ❑ Hereditary hemochromatosis
  - ❑ Galactosemia
  - ❑ G6PD
  - ❑ Homocystinuria
  - ❑ Biotinidase deficiency
  - ❑ Familial Hypercholesterolemia
- 

## *Part II*

### **1. Name Limitations to writing out the family medical history**

Writing out a family medical history using words works. However, it can be more time consuming to write and read than a medical pedigree. Furthermore, the relationships among the individuals are not always clear when the information is written out. Aunts, uncles, grandparents, and cousins could be related either through the individual's mother or father. Even when the side of the family is specified for each relative, it can be difficult to keep track of different branches of the family tree. Also, when a family medical history is written it is more difficult to see inheritance patterns than when it is drawn in pedigree form.

### **2. Draw your own pedigree (each pedigree will vary)**

---

## *Part III*

### **1. Genes contain the information for making which of the following...**

- a) carbohydrates
- b) proteins
- c) amino acids
- d) all of the above
- e) none of the above

b) proteins -- Genes are made of DNA. DNA is a code to tell the body the order in which amino acids should be linked together to form a protein.

### **2. Which of the following statements is NOT true...**

- a) Changes in DNA can occur in nearly any cell in the body
- b) Changes in DNA can lead to cancer
- c) Changes in DNA are not always passed on to children

- d) Changes in DNA can be due to environmental exposures
- e) Changes in DNA usually lead to disease

e) is the only statement that is **NOT TRUE** -- This is because changes in DNA usually **do not** lead to disease. Many changes are repaired before a cell divide, other changes are protective against disease, some genetic changes contribute to the variability we see between different individuals and still other changes are neutral or do not have an effect. **All of the other statements are TRUE.**

---

#### *Part IV*

### **1. What is the chance that the next child will have PKU assuming that the parents already have two children both with PKU?**

Because PKU is autosomal recessive, there is a **25% chance** with EACH pregnancy. The risk is the same regardless of whether or not they have two children with PKU.

### **2. What is the chance that the next child won't have PKU given the scenario above?**

When both parents are carriers there is a **75% chance** that the child won't have PKU. There is a 25% chance that the child will inherit two functional gene copies. There is a 50% chance that the child will inherit one mutation and be a carrier like the parents. Carriers of a recessive gene mutation do not have symptoms.

### **3. The chance that a woman with PKU will have a child with PKU is?**

d) Cannot be determined from the information provided

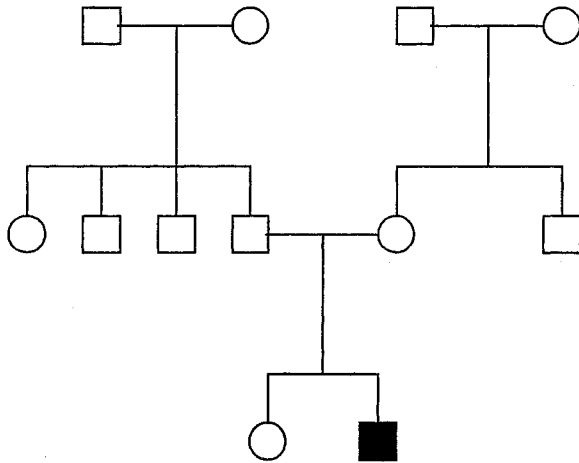
The chance of her having a child with PKU depends on whether or not the father of the child is a carrier for PKU. If you were told the frequency of carriers among individuals from the father's ethnic population, it would be possible to calculate a risk based on this information. However, since this information is not provided to you the risk cannot be accurately assessed.

### **4. Do individuals that inherit an autosomal dominant gene mutation always have symptoms or characteristics of the disorder?**

**NO!** Sometimes individuals with autosomal dominant gene mutations do not show very many signs of the condition and may remain undiagnosed. Other times, an individual will never develop the symptoms that are attributed to the gene mutation. For example, there are gene mutations that when inherited

will significantly increase the risk for cancer. However an increased risk doesn't necessarily mean the individual will develop the disease.

5. Which of the following could be the underlying cause of the shaded individual's disease?



When an individual has a disease in the *absence* of a family history there are a number of potential explanations. Therefore the answer is...

d) all of the above

Along with other possible explanations...

- ❑ His condition could have resulted from a new dominant mutation that occurred in the egg or sperm.
- ❑ His parents could each be carriers of the same autosomal recessive disorder and both transmitted their gene mutations to him.
- ❑ The condition could be due to both genetic susceptibility and environmental factors.

6. What are the risks to the pregnancy if the Father is affected and the condition is inherited in an autosomal dominant fashion?

Based on the pedigree it is possible that the inheritance pattern is autosomal dominant. If this were the case than there is a **50% chance** with each pregnancy that a child will inherit the genetic mutation from the parent. However, whether or not they develop the condition often depends on other factors including what condition the family has.

7. What are the risks to the pregnancy if the father is affected and the condition has a maternal (mitochondrial) inheritance pattern?

The risk of getting a maternally inherited condition if your father is affected is **VIRTUALLY 0%** since nearly all mitochondria are inherited from your mother. (We never quote 0% for any genetic risk ). On the other hand, the risk is closer to 100% if it is the mother that is affected with the condition.

8. There are a number of genetic counselors in the Cincinnati area. Anyone of these would be correct.

9. List the three "red flags" (characteristics in a medical family history that suggest a condition may have a significant genetic component) that you think you will see most often in families of your future patients/clients (see link to [red flags](#) for a list)

10. Which of the following is/are roles genetic counselors perform?

- A) Assess the risk that an individual will have a genetic disorder based on family history and/or data from population genetic studies
- B) Provide information about what challenges or health problems an individual with a genetic condition may experience
- C) Recommend that a couple should have an abortion based on the seriousness of a genetic condition
- D) All of the above
- E) a & b

The role of a genetic counselor is to provide individuals or couples with information about genetic risks and then support them in making informed decisions that they feel are best under their specific circumstances. They also may also have a number of other roles. However, they do not tell couples whether or not they should have an abortion. (They also **DO NOT** tell couples whether or not to have children.) Therefore only **a and b** are true.

## Appendix D: Pedigree

**DRAWING YOUR FAMILY PEDIGREE...** (adapted from the [New South Wales Genetics Education Program](#))

Read all of the directions carefully before starting. Aim to draw your pedigree showing 3 or 4 generations. It is not always possible to complete your pedigree because of adoption, lack of reliable information, or distance from your family. If you do not know much about your family history or if you do not feel comfortable drawing your own pedigree, try drawing a pedigree by having your friend tell you her/his family history.

## WHY DRAW YOUR FAMILY PEDIGREE?

- ❑ Many diseases or disorders tend to "run in families", that is, they can be inherited. Some of these disorders are present at birth; others do not appear until late childhood or in adult life. Some genes can cause a specific disorder while others can simply render someone **more likely** to develop a certain disorder (predisposing genes).
  - ❑ In some disorders, early diagnosis - sometimes even before the symptoms appear - can lead to specific treatment.
  - ❑ An awareness of any disorders, which run in your family, may be useful for you and the early diagnosis, treatment and/or prevention of hereditary disease.
  - ❑ Try to determine the genetic risks in your family **after** you complete the genetics tutorial.
  - ❑ Would you or your family benefit from genetic counseling?
- 

## FAMILY HEALTH PROBLEMS TO INCLUDE ON YOUR FAMILY PEDIGREE

Many disorders have now been recognized as occurring more frequently in some families than others. Also, certain nationalities and ethnic groups may be more likely to have certain inherited disorders. The following list does not cover all genetic disorders but includes some conditions, which should be noted in your family pedigree.

- ❑ Blood Disorders: hemophilia or other bleeding problems, thalassaemia, sickle cell disease & Rh disease.
- ❑ Cancer: bowel, breast, colon, lung, melanoma, ovarian, stomach, etc
- ❑ Cardiovascular: high blood pressure, heart disease, high cholesterol
- ❑ Chromosomal abnormalities: such as Down syndrome or Turner Syndrome
- ❑ Cystic Fibrosis
- ❑ Diabetes
- ❑ Epilepsy
- ❑ Eye Disorders: blindness, cataracts, glaucoma, retinitis pigmentosa
- ❑ Hearing loss
- ❑ Kidney Disease
- ❑ Liver Disease
- ❑ Mental Retardation or learning difficulties
- ❑ Muscular/skeletal: short stature/dwarfism, muscular dystrophy, arthritis
- ❑ Neurological/Psychiatric: Huntington disease, manic-depressive illness, schizophrenia, Parkinson's
- ❑ PKU (Phenylketonuria)
- ❑ Respiratory: asthma, allergies, emphysema
- ❑ Skin Disorders: psoriasis, moles, eczema
- ❑ Tay Sachs Disease
- ❑ Other genetic disorders

If you have listed any of the above on your family pedigree, you should be aware that inheritance might play a role.

---

## SYMBOLS TO USE WHILE DRAWING A PEDIGREE... (Refer to the symbols below)

If you don't remember all of the symbols when you are practicing, don't worry! Genetics, with all its symbols and terminology, is like a new language; you just have to use it to really learn it.

**NOTE:** You will need to create your own shaded symbols for each condition. Include a key that defines what your symbols mean.

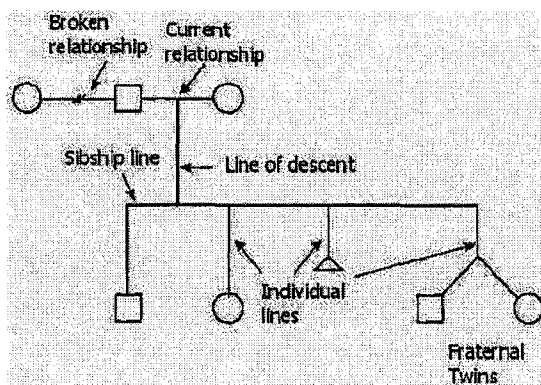
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### OTHER ITEMS TO REMEMBER TO INCLUDE...

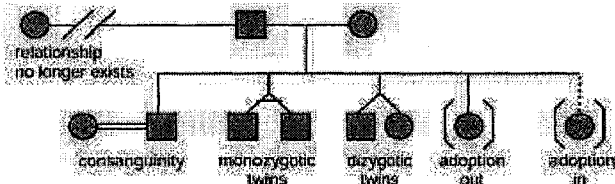
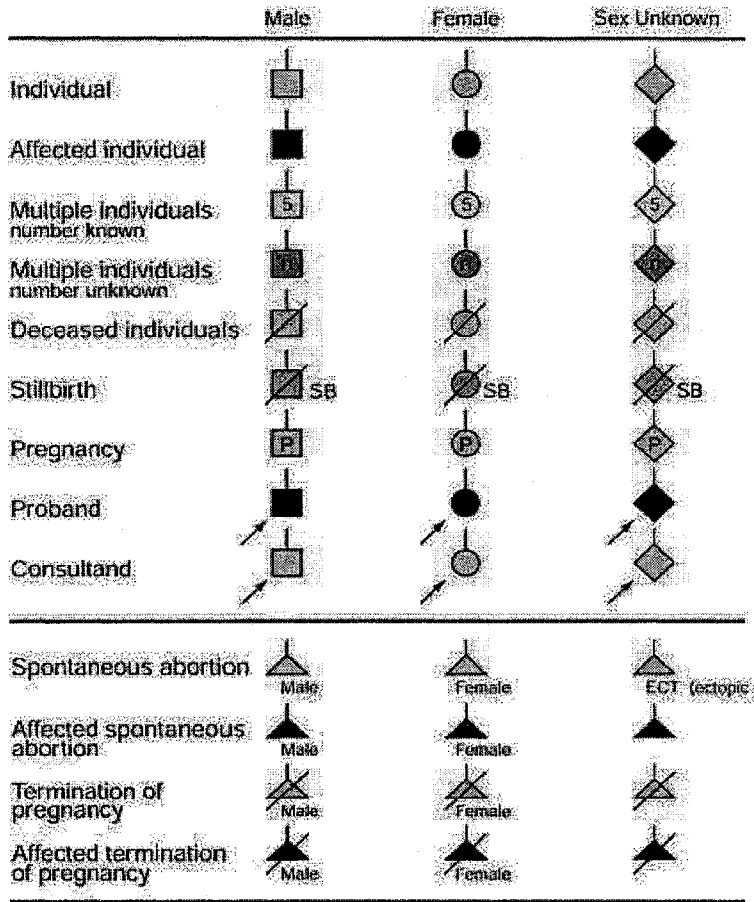
- ❑ Date history was taken
- ❑ Name of person taking the pedigree
- ❑ Name(s) of person(s) providing the information (HISTORIAN)
- ❑ Whether individuals are alive or deceased
- ❑ Age and cause of death
- ❑ The age of onset of the diseases
- ❑ Ethnicity
- ❑ Parental consanguinity (couples related by blood)

---

### PEDIGREE SYMBOLS AND LINES



- ❑ Couples are connected with a horizontal *relationship line* between symbols
- ❑ Children are located **below** their parents and are connected to them with a vertical *line of descent*
- ❑ Full biological brothers and sisters are connected to each other by a horizontal *sibship line* drawn **above** them and connects their individual lines



## HOW DO I BEGIN?

- Start by drawing either a square or circle (to represent yourself) in the center across from generation III on the page of your answer sheet entitled **“Part II: Pedigree”**
- Draw in squares and/or circles next to your symbol to represent all of your sisters and brothers
- Draw in vertical *individual lines* for each person and connect all full biological siblings with a horizontal *sibship line*
- Draw parents above the children and connect the parents to each other with a horizontal *relationship line*
- Draw a *line of descent* from the parents to their biological children
- Repeat the necessary steps to draw in grandparents and your children (if any)
- OPTIONAL: You may choose to include aunts, uncles and cousins as well as your spouse’s side of the family
- Fill in important medical details for all of family members using the above guidelines...

## Appendix E: Lecture Presentation

### Where Do Health Care Professionals in Nutrition Stand?

Survey of graduates in the Nutritional Sciences Department at the University of Cincinnati

- Most either didn't recognize how genetics impacts their profession or failed to respond to this question
- Majority were interested in learning more about genetics and it's potential impact for their career
- Most reported common diseases such as heart disease, diabetes, and hypertension as the most prevalent diagnoses among their clients
- Many individuals reported interest in learning more about the genetics of these common diseases

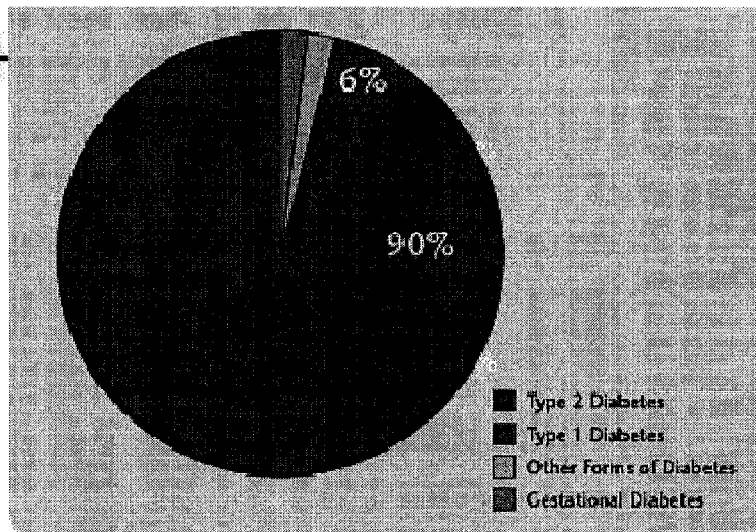
### What I Hope You Will Gain

- An understanding of the role genetics plays in different types of diabetes mellitus
- Skills to help you recognize different inheritance patterns and causes of diabetes
- The knowledge and/or resources you need to answer basic questions you may be asked about diabetes and genetics
- The ability to recognize your limitations and identify individuals who may benefit from a genetics consultation

## Diabetes Mellitus (DM)

- Group of diseases in which high levels of glucose accumulate in the blood
- Number of different types of DM believed to have different underlying causes
- Some types of DM have a stronger genetic basis than other types

## Types Of DM



## How does DM affect the body?

- After a meal, your body breaks food down into glucose
  - Insulin helps cells take up glucose to be used as fuel
  - In individuals with DM
    - Beta cells in the pancreas do not make or secrete enough insulin
- and/or**
- Cells in the body are not responding to insulin properly
  - Glucose builds up in the bloodstream where it can cause damage to body tissues

## Symptoms of DM

### **Type 1 Diabetes:**

- Frequent urination
- Unusual thirst
- Extreme hunger
- Unusual weight loss
- Extreme fatigue
- Irritability

### **Type 2 Diabetes:**

- Any of the type 1 symptoms
- Frequent or recurring infections
- Blurred vision
- Cuts/bruises that are slow to heal
- Tingling/numbness in the hands or feet

**\*Not all people with T2 DM have symptoms**

## Ketoacidosis

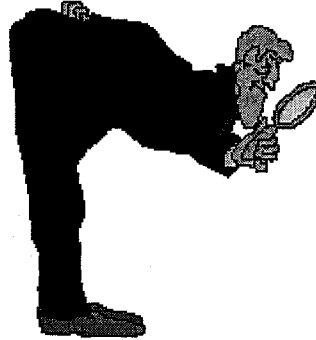
- When insulin is not present, our bodies use fat as fuel
- By-products of fat metabolism are called ketones
- Excessive ketones can lead to ketoacidosis
- Rare in Type 2 DM more common in Type 1 DM
- Symptoms include
  - Blood-glucose > 300 mg/dL
  - Frequent urination
  - Fatigue
  - Vomiting
  - Muscle stiffness and aching
  - Rapid deep breathing
  - Fruity smelling breath
  - Mental stupor that can progress to a coma

## Why Is DM Important?

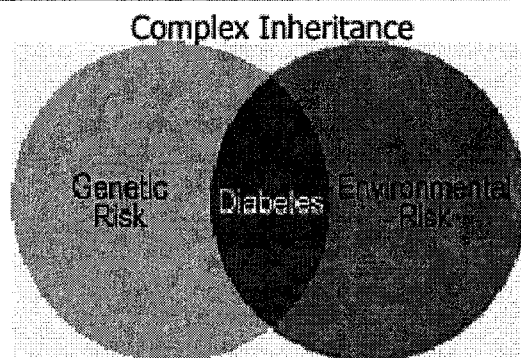
- Affects ~16-17 million people in the US  
(~ 5 million of these remain undiagnosed)
- Nearly 20.1% of individuals 65 and older in the U.S. have diabetes
- Prevalence of type 2 DM is increasing
- Costs the US ~\$100 billion annually  
(\$44 billion in direct medical costs related to diabetes remainder is indirect costs due to disability, lost work, etc.)
- DM is a major contributor to heart disease, stroke, blindness, kidney disease, nerve damage and other medical problems
- **The effects of DM can sometimes be delayed, minimized or prevented if risk is identified early**

## Questions to follow up with when gathering information...

- What type of DM is it?
- At what age were they diagnosed?
- Do they require insulin or is it controlled by diet and/or medication?
- Are they overweight?
- Are there other family members with DM?
- Any family members with kidney disease, stroke, eye problems or heart disease?
- Family members with autoimmune problems (thyroid problems etc.)
- Any infections of the pancreas or other serious illnesses?
- Any family members with any of the symptoms of DM?



## Inheritance Patterns Associated with DM



Most cases of diabetes are thought to be caused by a combination of environmental factors and more than one predisposing gene




## Types of DM with Complex Inheritance

---

### **Type 1 diabetes mellitus (T1 DM)**

- Most common cause of DM in children and adolescents
- Insulin is required for treatment
- Not correlated with obesity
- Having a close relative with T1 DM significantly increases an individual's chance of also having T1 DM
- However, only 5% of individuals with T1 DM have a relative with T1 DM



## Types of DM With Complex Inheritance (continued)

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### **Type 2 diabetes mellitus (T2 DM)**

- Usually occurs after the age of 40, but the age of onset is decreasing
- May or may not require insulin
- Highly correlated with obesity
- Genetics is believed to play a larger role in causing T2 DM than it does in T1 DM
- Risks for T2 DM can be significantly reduced with changes in lifestyle

## Autosomal Dominant Inheritance Patterns of DM

### **Maturity Onset-type Diabetes of the Young (MODY)**

- Usually presents as a mild form of T2 DM with gradual onset of symptoms
- Usually occurs in multiple individuals and two or more generations within the family
- Occurs at an earlier age of onset than seen in the general population (at least one family member must be diagnosed before age 25)
- Less likely to be correlated with obesity than is the case with typical T2 DM
- More common in Caucasians
- Multiple MODY genes have been identified

## Autosomal Dominant Inheritance Patterns of DM (continued)

### **Atypical Diabetes Mellitus (ADM)**

- Usually associated with a strong family history and onset before age 40
- May have acute onset of severe symptoms including ketoacidosis (similar to onset of type 1 DM)
- Later follows a non-insulin dependent course (more similar to T2 DM)
- More likely to be associated with obesity than classic MODY
- Most common in African Americans
- May account for up to 10% of youth onset diabetes in African Americans

## Maternally Inherited DM

- **Maternally Inherited Diabetes and Deafness (MIDD)**
  - Accounts for ~1% of all cases of diabetes
  - Age of onset and severity varies
  - Over half develop some hearing loss
  - Affected women usually pass it on to most of their children of which 80% are affected by age 70
- **Other mitochondrial conditions**
  - Diabetes is one of the symptoms that can be associated with other mitochondrial diseases
  - These other mitochondrial disorders usually present with other symptoms such as...
    - persistent lactic acidosis, muscle weakness, low muscle tone, failure to thrive, and seizures

## Diabetes Secondary to Other Conditions

- Conditions that damage or destroy the pancreas
  - Pancreatitis
  - Pancreatic surgery
  - Specific industrial chemicals
- Certain drugs can cause temporary diabetes
  - corticosteroids, beta-blockers, and phenytoin
- Rare genetic disorders may increase risk for diabetes
- Hormonal disorders may increase risk for diabetes
  - Acromegaly, Cushing's syndrome, pheochromocytoma, hyperthyroidism, somatostatinoma, aldosteronoma

## Appendix F: Case-based problems

### Group/Pair Discussion:

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- Read your assigned case scenario and review the pedigree if you have one
  
- Answer the questions for your case by using...
  - Your knowledge of genetics and inheritance patterns
  - The handout attached to the case scenarios

### Case 1

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Mrs. White brought her only son, Mike, in to see you when he was diagnosed with diabetes one year ago at age 8. At that time you helped counsel Mrs. White about tips on managing his diet. Mike requires daily insulin shots. At this visit Mrs. White reports to you that she is pregnant. She is concerned about the chance this baby will also develop diabetes. Nobody else in the family has diabetes and the family history is negative for diabetes related symptoms or complications.

How would you answer Mrs. White's questions on the following slide?

## Questions for Case 1

1. 1. What is the chance my baby will have diabetes?
2. 2. I heard diabetes can be caused by drinking cow's milk. I fed my son Mike cow's milk because I have inverted nipples. What should I feed this baby since I can't breast feed?
3. 3. I also heard diabetes is inherited, so why don't other members of my family have it? Are we the exception to this?
4. 4. Would you refer her for genetic counseling? Why or why not?

## Case 2

Ms. Walker is a 17 year-old Caucasian woman who was just enrolled with WIC after finding out she is 6 weeks pregnant. During your visit you discover she has had diabetes for 8 years and is on insulin. Upon further discussion she discloses that she does not keep tight control of her blood glucose level, the pregnancy was unplanned and she has not seen a physician in over 6 months.

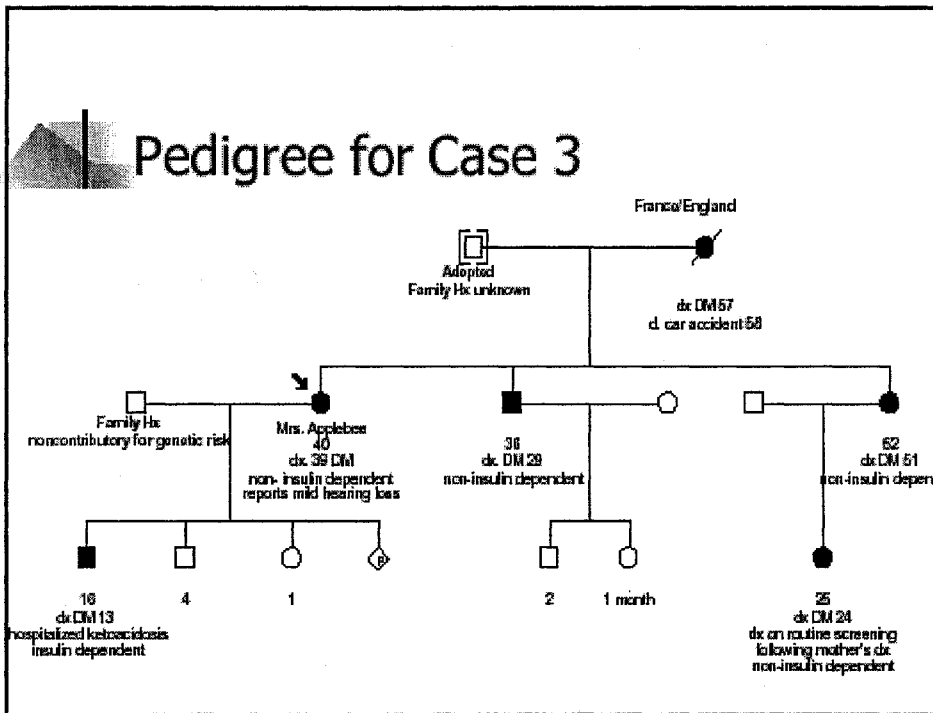
Answer the following questions...

## Questions for Case 2

1. 1. Based on her history of diabetes what are her risks with this pregnancy?
2. 2. What would you say that might encourage her to seek medical attention?
3. 3. Would a genetic counselor be an appropriate person to be involved in Ms. Walker's health care? Why or why not?
4. 4. If Ms. Walker were to plan a pregnancy in the future, what recommendations should she be given about nutrition and health care related to her diabetes?

## Case 3

Mrs. Applebee comes to you to discuss ways to help her control her diabetes. She was only diagnosed with diabetes one year ago. This pregnancy has motivated her to learn ways to control her diabetes so she can reduce potential pregnancy complications. During your discussion she mentions that her son also has a diagnosis of diabetes, but his is more serious and requires insulin. Since this seems unusual you ask more about the family history. (Review the following pedigree for details on the family history).



- ## Questions for Case 3
1. List at least two reasons why this family history seems unusual?
  2. What type of inheritance does this pedigree best fit? Why?
  3. Describe what may potentially be the cause of diabetes in this family and explain why.
  4. Would a referral to genetics be appropriate? If so, what are some of the things that would likely be discussed at a genetic counseling session?

## Case 4

A 17 year-old boy, Joe Blow, was recently diagnosed with DM after experiencing a wound on his knee that wasn't healing. You can't help but notice that Joe Blow and his sister, Jane, are both extremely overweight. You decide to take a family medical history and discover that Joe's mother was diagnosed with DM at age 43 and is currently taking oral medication to help control her diabetes. Joe's dad is obese and has high cholesterol and high triglyceride levels. He was found to have glucose intolerance following his most recent diabetes screening test. There are no other family members known to have diabetes or diabetes associated symptoms or complications. Both sides of the family are of Northern European descent.

## Questions for Case 4

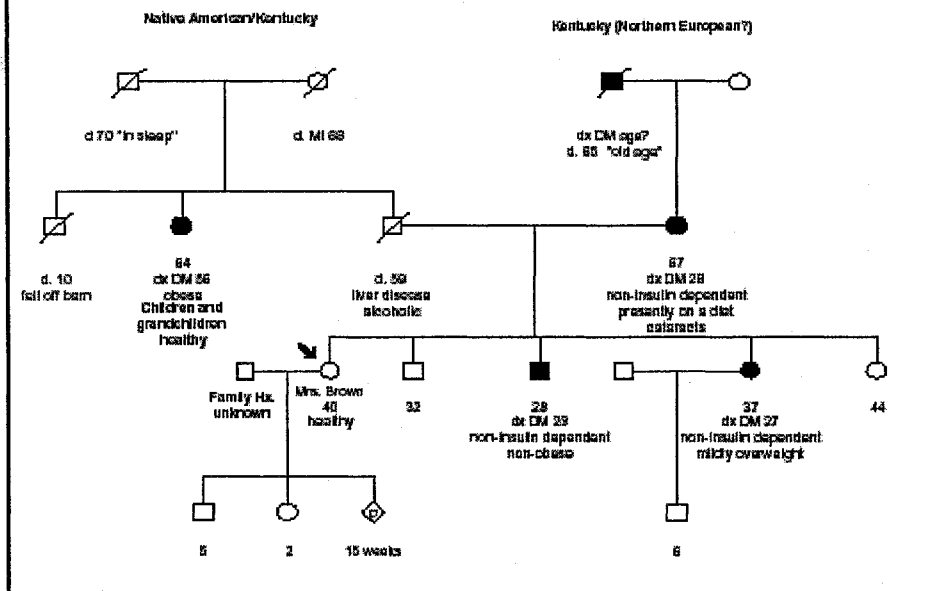
1. Based on the family history as well as the prevalence and characteristics of different types of diabetes, what is the most likely type of diabetes in this family? Why?
2. How would you respond when asked to explain Jane's risk for diabetes and how she can reduce that risk?
3. Would any type of testing or screening be recommended or available for Jane either now or in the future? If so what type of testing or screening?
4. If this family were of a different ethnicity (i.e. Pima Indian) would that change your answers to any of the questions above? Why or why not?

## Case 5

Mrs. Brown asks you to discuss ways to reduce her risk for diabetes. A number of her family members were diagnosed with diabetes under the age of 40. She is especially concerned because her brother got diabetes at age 23 despite the fact that he exercises and eats a healthy diet.

Review the pedigree on the following slide.

### Pedigree for Case 5



## Questions for Case 5

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1. 1. What might be the explanation for DM in this family? Why?
2. 2. How can Mrs. Brown reduce her risks?
3. 3. Would you counsel differently if her family members had all been diagnosed after age 40?
4. 4. Is a genetics referral appropriate for Mrs. Brown? Why or why not?

## Take Home Message

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- Most individuals you encounter with DM or a positive family history of DM will probably have T2 DM
- In these cases you can help play a major role in prevention by...
  - Identifying individuals AND family members at increased risk
  - Discussing ways of reducing those risks
- You will also likely see individuals with T1 DM
- In these cases you may play a role in education by...
  - Discussing current controversies about contributing risk factors (such as the role of cow's milk in causing T1 DM)
  - Explaining complex inheritance and risks to family members

## Take Home Message (cont.)

- It is less likely that you will encounter a family history like some of the ones we discussed

### HOWEVER...

- Skills to identify individuals with a significantly increased genetic risk are necessary to make appropriate referrals to genetics
- Knowing that in some cases genes play a major role will help you understand why dietary interventions will sometimes prove ineffective at reducing risks or symptoms in some common conditions

## Summary

- The two most common forms of diabetes (T1 & T2 DM) are complex diseases
- T2 DM has a stronger genetic component than T1 DM
- Dietary and lifestyle changes can prevent, delay onset, or reduce complications of T2 DM
- Even though clinical testing for some DM susceptibility genes is available there are presently no cures or treatments based on these results that have been proven effective
- **HOWEVER**, the discovery of genes that predispose to diabetes may lead to individualized treatment in the future

## **Appendix G: Reference materials for cases**

### **Clues to Distinguish Different Types of Diabetes Mellitus in Children, Adolescents and Young Adults**

#### **Children/adolescents with immune mediated T1 DM**

- Most common cause of DM in children and adolescents
- Risk is not correlated with obesity
- Often have acute onset and severe symptoms (ketoacidosis)
- No clear inheritance pattern
- Inherited genetic susceptibility
- However, only 5% will have a relative with T1 DM
- Most will test positive for autoantibodies associated with the destruction of the pancreas
- Other autoimmune disorders may be present in the family or individual
- Most common in Caucasians
- Rare in African American children

#### **Children/adolescents with “typical” T2 DM**

- Usually associated with childhood obesity
- Symptoms usually develop gradually
- Ketoacidosis is not commonly seen except under conditions of severe stress
- Strong genetic association
- Children/ adolescents with typical T2 DM usually have a family history of T2 DM without a clearly dominant inheritance pattern
  - 74-100% have 1st or 2nd degree relative with T2 DM
  - 45-80% have at least one parent with T2 DM
- Acanthosis nigricans (velvety, hyperpigmented thickening of the skin resulting from the presence of high insulin levels) may be present in up to 90% of children with T2 DM
- Polycystic ovary syndrome will often co-occur with T2 DM

#### **Classic MODY**

- T2 DM in two or more generations with AD inheritance pattern
- One individual in family must have a diagnosis of T2 DM before age 25
- Usually gradual onset and mild symptoms
- Less likely obese than individuals with “typical” T2 DM
- More common in Caucasians

#### **Atypical Diabetes Mellitus (ADM)**

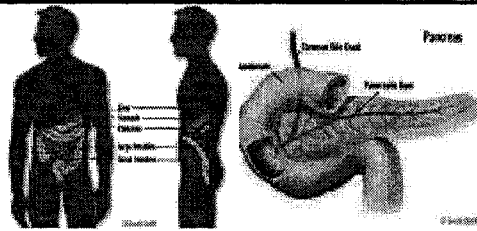
- Family history of early onset DM (before age 40)
- AD inheritance (75% of families have a multigenerational pattern)

- Often presents initially with acute onset and severe symptoms (ketoacidosis)
- May be insulin dependent initially
- Later insulin may no longer be necessary to maintain proper glucose levels
- More likely obese than individuals with classic MODY (~50% are obese)
- Most common in African Americans
- Accounts for ~ 10% of youth onset DM in African Americans

#### **Maternally Inherited Diabetes and Deafness (MIDD)**

- Inherited only from the mother, not passed on by an affected father
- DM can develop in childhood or adulthood for different individuals (even in the same family)
- The severity of the DM varies even within the same family (some individuals will require insulin and others will not)
- Over half of affected individuals will eventually develop some degree of hearing loss
- Hearing loss does not generally progress to complete deafness

## T1 DM



- Previously called childhood onset diabetes or Insulin Dependent Diabetes Mellitus (IDDM)
- Usually occurs when the immune system destroys the beta cells in the pancreas that produce insulin
- May also be idiopathic (cause unknown)
- Requires regular insulin injections in order to control blood sugar level
- Generally develops during childhood or puberty, but can occur at any age

## Who is affected with T1 DM?

- Affects 700,000 people in the United States
- Most common in Caucasian populations, especially those from Scandinavia
- Rare in people of Asian or African descent

## What Increases Risk for T1 DM?

### Environmental Factors (studies not conclusive)

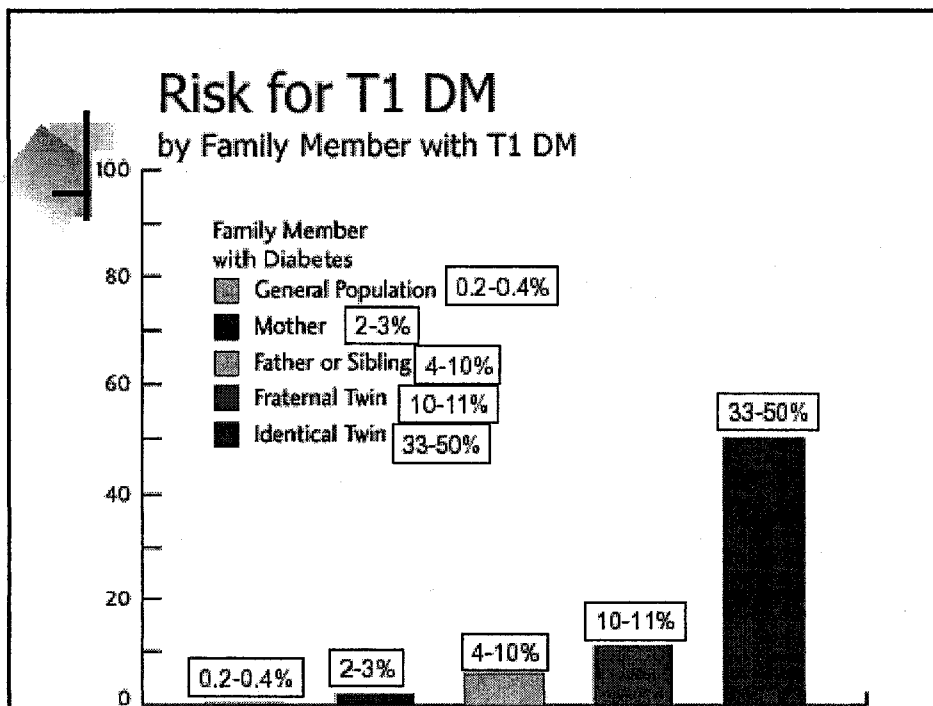
- Exposure to viruses???
- Earlier age of exposure to cow's milk???
  - A number of retrospective studies show a correlation between T1 DM and being fed cow's milk as an infant
  - Two well designed prospective studies fail to show a link though

### Genetic Factors

- Close relative with T1 DM (see chart on next slide)
- Those with known susceptibility genes (see slide on HLA genes)
- Individuals from N. Europe and specific Mediterranean groups (i.e. Sardinians)

### Autoimmune Factors

- Individuals with diabetes-associated autoantibodies
- Individuals with other autoimmune diseases (diseases that result from the immune system destroying the body's own tissues)



## Treatment of T1 DM

Lack of insulin production by the pancreas makes type 1 diabetes particularly difficult to control. Treatment requires a strict regimen that typically includes...

- carefully calculated diet
- planned physical activity
- home blood glucose testing several times a day
- multiple daily insulin injections

## Implicated Genes in T1 DM

- Researchers have found at least 18 genetic locations that are related to T1 DM susceptibility
- Not all of the genes that put a person at risk for T1 DM are known
- *No* single gene can predict whether or not a person will get T1 DM with certainty
- At least two different genes in the HLA region are significantly correlated with risk of T1 DM

## T1 DM: HLA-DQB1 polymorphisms (gene variations)

- HLA-DQB1 0201, 0302, 02 associated with increased risk for type 1 DM
- HLA-DQB1 0602, 0603, 0301 seem to be protective

## Type 1 DM: HLA-DR Polymorphisms

DR2	protective
DR3	Significant risk
DR4	Significant risk
DR5	Slight risk
DR6	Neutral/protective
DR7	Protective

## Genetic Testing for T1 DM

- Knowing a person's genotype or (type of gene variations he/she inherited) is not entirely predictive
- A large proportion of unaffected individuals carry high risk alleles
- Genetic testing is available, which can modify risk (determine if it is higher or lower) based on whether individuals share HLA genes with the family member who has type 1 DM
- Even if genetic testing reveals that a person has an increased risk for T1 DM, there are presently no prevention strategies that have proven effective in scientific studies

## T1 DM Risk Based on Shared HLA Genotype with Affected Relative

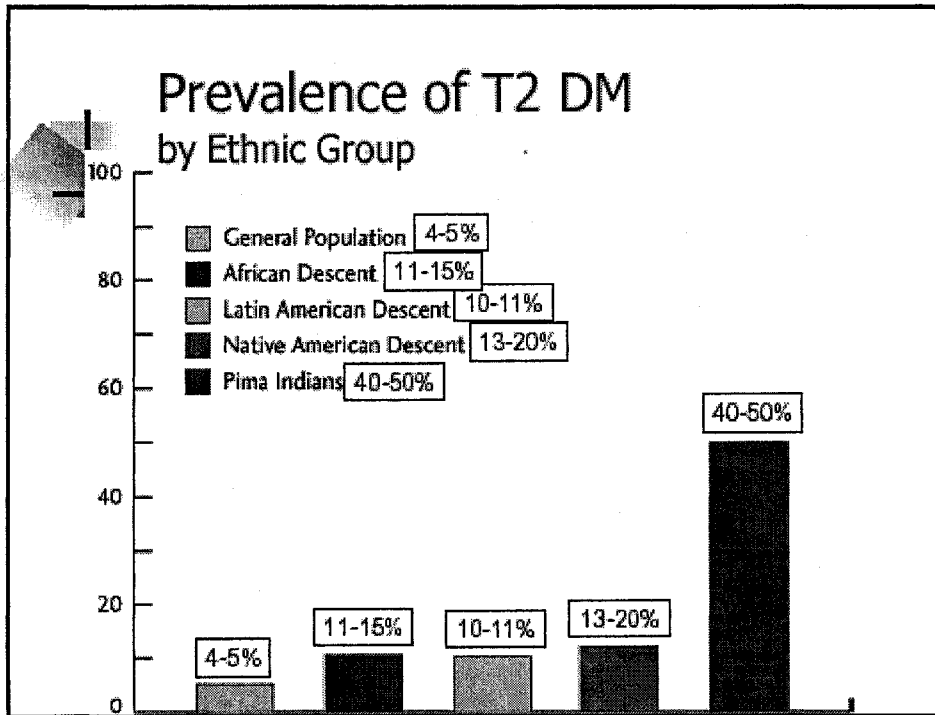
- Siblings with a shared HLA-identity (all of their HLA genes are the same) are at a 10-30% risk for T1 DM
- Siblings with shared HLA-haplotype (half of their HLA genes are the same) are at 4-9% risk
- HLA non-identical siblings (none of their HLA genes are the same) are not at significantly increased risk above the population risk of 0.4%
- Risk is unknown for more distant relatives who have a shared HLA haplotype
- *However*, based on risk estimates it is not very likely that second-degree relatives would develop T1 DM

## T2 DM "Typical"

- Formerly called adult onset diabetes or Non-Insulin Dependent Diabetes Mellitus (NIDDM)
- By far the most common form of DM
- May need to take insulin, but many can keep their blood sugar at an acceptable level by...
  - modifying diet
  - getting regular exercise
  - taking medication that helps their body use insulin more effectively
- Usually affects adults older than 40 years, but can occur in adolescents and even children
- Most common in adults over 55

## What Increases Risk for T2 DM?

- Age (most individuals with T2 DM are over age 55)
- Obesity (particularly around the abdomen)
  - ~85% of individuals with T2 DM are obese
  - Believed to make the body tissues less sensitive to insulin
- Sedentary lifestyle
- HDL cholesterol less than 35 and/or triglyceride level greater than 250
- Ethnicity (refer to chart on the following slide)
- Family history of T2 DM (see risk to family members chart for details)
- Previously identified to have impaired glucose tolerance
- Women who have had gestational diabetes or a baby larger than 9 lbs



### Why the Wide Variability in T2 DM Prevalence Among Different Ethnic Populations?

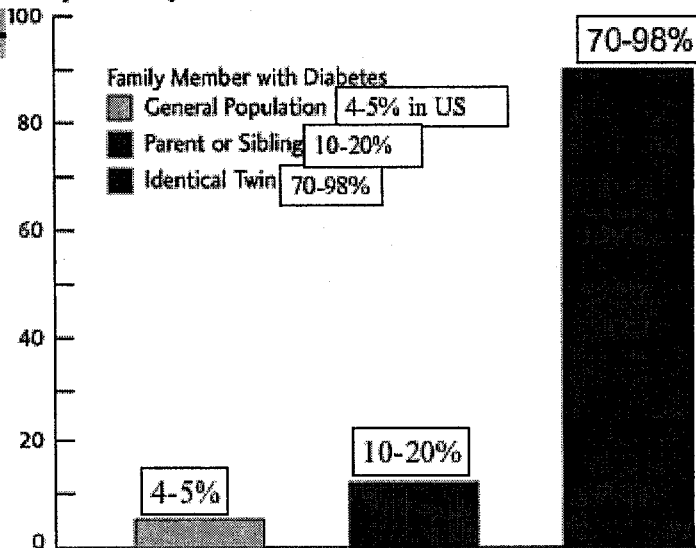
- Most likely, ethnic groups at high risk have polymorphisms (gene variants) that increase risk for obesity and T2 DM
- Environment determines whether a gene is helpful or harmful
- Certain polymorphisms may be advantageous when food is scarce
- When food is plentiful they may cause increased risk for disease

Some polymorphisms that confer increased susceptibility in high risk populations have already been discovered!

## Type 2 DM: Risks for Family Members

- Risks vary according to study design and ethnicity of the group studied
- Empiric population risks may not be representative of your family depending on their ethnicity
- **BEWARE** of how the risks are defined  
(note how glucose intolerance is included as part of the risk figure below, but is not included in the risk on the following slide)
- Children or siblings of an individual with T2 DM have a 33-40% risk of developing T2 DM **or** *glucose intolerance*

## Risk for T2 DM by family member with diabetes





## Treatment for T2 DM

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- Treatment typically includes...
  - Dietary control
  - Exercise
  - Home blood glucose testing
  - In some cases, oral medication and/or insulin (up to 40 percent of people with type 2 diabetes require insulin injections)



## Difficulties Finding Genes for T2 DM

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- A number of genes are thought to contribute to risk
- Susceptibility genes may be different among different ethnic populations
- Large environmental influence --  
"We 'inherit' both our genes and our lifestyle"

## The Role of the Beta 3-Adrenergic Receptor Gene in Type 2 DM

- Makes a protein in fat cells that is involved in determining how much fuel your body burns when you are resting
- People with two copies of the TRP64ARG allele...
  - Are more obese
  - Have slower metabolism
  - Have a hard time losing weight
  - Develop diabetes at an earlier age
- TRP64ARG is four times more common in Pima Indians than in people of European descent, and one and a half times more common in people of African or Mexican descent

## Screening and Genetic Testing for T2 DM

- T2 DM is not usually inherited in a clearly dominant or recessive manner
- With so many variables to consider we are a long way from **predictive** genetic testing  
(at least for the general population)
- American Diabetes Association recommends screening for diabetes onset every three years for **high risk individuals**  
(see next slide for details)
- Screening includes a fasting glucose test or glucose tolerance test

## Diabetes Screening Recommendations

- Test at age 45 (repeat every 3 years)
- Test before age 45 (repeat every 3 years or more frequently) if one or more of following risk factors is present
  - Obesity
  - First-degree relative with DM
  - Member of high-risk ethnic group (Black, Hispanic, Native American)
  - Hypertensive (above 140/90)
  - High cholesterol and/or triglyceride level
  - History of gestational diabetes or delivering a baby weighing more than 9 lbs

## Risk Reduction for T2 DM is Possible!!!

- Studies in high-risk groups (defined as those with impaired glucose intolerance) suggest...
  - Development can be reduced by more than 50% with dietary and exercise interventions
- Recommendations
  - Avoid weight gain or lose weight
  - Healthy low-fat, high fiber diet
  - Exercise regularly

## Maturity Onset Diabetes of the Young (MODY)

- Small subgroup of people with T2 DM usually develop the disease before age 25
- Most people in this group have a strong family history of diabetes and are less likely to be obese than others with T2 DM
- Most often presents with subtle symptoms and gradual onset
- Not associated with destruction of the insulin producing pancreatic cells as in most individuals with T1 DM

## Inheritance of MODY

- Autosomal dominant inheritance pattern
- Accounts for 1-5% of all T2 DM cases
- Clinically and genetically heterogeneous conditions (Symptoms and natural history can present differently largely based on which gene has a mutation)
- So far, five genes identified that can put a person at risk for developing MODY
- ~85% of Caucasians with MODY have a mutation in MODY1, MODY2 or MODY3 genes
- Mutations in these three genes cause interference with the normal release of insulin by the pancreas
- Most individuals who inherit one of these gene mutations will develop diabetes

## Treatment for MODY

- Treatment is based on severity (Which can be predicted somewhat by the type of MODY gene mutation)
  - In some individuals diabetes is progressive and may eventually require insulin
  - Other individuals have a milder course that does not tend to progress
- Even if a mutation is found there are no known ways to prevent or delay diabetes onset at this time

## Atypical Diabetes Mellitus (ADM)

- Some categorize this as idiopathic T1 DM because it usually presents with acute onset and severe symptoms, but is not associated with the destruction of pancreatic cells
- Others categorize it as a subtype of MODY because it is seen in young individuals with a multigenerational family history of early onset DM
- Susceptibility gene(s) is/are presently unknown

## Maternally Inherited Diabetes and Deafness (MIDD)

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- Accounts for up to 1% of all diabetes cases
- Age of onset and severity varies...
  - Half originally diagnosed with T1 DM (these people developed a severe form of diabetes at a young age)
  - Other half diagnosed with T2 DM (these people developed a mild form of diabetes late in life)
- ~ 60% develop some mild hearing loss (especially of high-frequency tones)
- Hearing loss *does not* generally progress to total deafness
- Women who are affected pass it on to most of their children (80% will have symptoms by age 70)
- As with other maternally inherited conditions affected males do not pass it on to their children

## Genetic Testing/ Treatment for MIDD

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- Genetic testing is available at a number of labs in the US for hearing loss and diabetes
- Potential for treatment with Co-enzyme Q10 ????
  - Some evidence suggests it may improve mitochondrial function and diabetes in some individuals
  - No studies have confirmed this yet
- Recognizing that diabetes is due to a maternally inherited condition changes genetic risks and counseling tremendously

## Diabetes in Pregnancy

- About 1 in 100 women of childbearing age has diabetes before pregnancy (pre-existing diabetes)
- Another 3 to 5 percent develop diabetes during pregnancy (gestational diabetes)
- Uncontrolled diabetes of any type poses risks for the pregnancy

## Gestational Diabetes

- Affects about four percent of all pregnancies
- Occurs more frequently in women with a family history of T2 DM and women from high risk populations
- The placenta makes a number of hormones that have a blocking effect on insulin
- In most women, the pancreas is able to produce enough insulin to compensate for this effect
- When it can't, gestational diabetes results
- Symptoms develop usually in 24<sup>th</sup> -28<sup>th</sup> week
- Symptoms usually mild
- Usually blood sugar returns to normal within a couple weeks after delivery
- Puts a woman at greater risk for developing T2 DM later

## Pregnancy and Diabetes: Complications and Risks

- Women with poorly controlled *pre-existing diabetes* in the early weeks of pregnancy are two to four times more likely than other women to have a baby with a serious birth defect such as a neural tube defect (NTD)
- Both women with poorly controlled **pre-existing DM and gestational diabetes** are at an increased risk for
  - Having a stillbirth
  - Having a very large baby >10 lbs
  - Experiencing complications during birth -- mostly due to increased size of the baby
  - Having a baby with low blood sugar, jaundice, or breathing difficulties after birth

## Recommendations for Women with Diabetes of Childbearing Age

- Consult a physician prior to pregnancy to make certain blood sugar levels are under good control (Maintaining normal blood sugar can reduce potential risks to the baby)
- Folic acid
  - Folic acid has been proven to reduce the incidence of neural tube defects (NTDs) in the general population and may reduce the risk of cleft lip and palate
  - Daily intake of a multivitamin (400 micrograms of folic acid)
  - A 10 X's higher dose may be prescribed by a physician for women with diabetes when planning a pregnancy, based on their increased risk for NTDs
  - Diet rich in foods containing folic acid

## Helpful Web Resources

- The American Diabetes Association "Healthy Habits to Help Manage and Prevent T2 DM" [www.diabetes.org](http://www.diabetes.org)
- The American Dietetic Association [www.eatright.org](http://www.eatright.org)
- MD consult [www.mdconsult.com](http://www.mdconsult.com)
- Diabetes Genes <http://www.ex.ac.uk/diabetesgenes/index.htm>
- Joslin Diabetes Center <http://www.joslin.harvard.edu>
- March of Dimes and NIH websites on pregnancy and diabetes
- More links can be found at <http://nutrition.genesoc.com>

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- See <http://nutrition.genesoc.com> for more references

## Appendix H: Test

### The Role of Genetics in Nutrition

p

Please fill in your 4-digit number in the spaces provided. \_\_\_\_\_

The purpose of this pretest is to assess your genetics knowledge. You are not expected to know all of the answers, but your answers are important because they will help determine what is taught in the curriculum in the future. **Your score on this test will not affect your grade in the course.**

*By completing this test you agree that your answers can be used in the study.*

This pretest consists of 20 true/false and multiple-choice questions. Please *select one* answer for each question

- 1) *True or False:* An individual's genetic test result has the potential to reveal information about the genetic status of his or her family members.
  - a) True
  - b) False
- 2) *True or False:* Individuals sometimes develop type 2 (adult onset) diabetes during childhood.
  - a) True
  - b) False
- 3) *True or False:* Some genetic disorders are more commonly found in people of specific ethnic backgrounds.
  - a) True
  - b) False
- 4) *True or False:* The majority of all health problems are believed to have some genetic component.
  - a) True
  - b) False
- 5) *True or False:* Dietary interventions can sometimes modify the chance that an individual will develop a condition for which they have a genetic predisposition.
  - a) True
  - b) False
- 6) *True or False:* Genetic testing is available that can sometimes help determine if an individual is at an increased risk for certain common diseases including heart disease, breast cancer, and colon cancer.
  - a) True
  - b) False
- 7) *True or False:* An individual is **more** likely to get diabetes if he/she has a family history of type 1 diabetes than if he/she has a family history of type 2 diabetes.
  - a) True
  - b) False
- 8) *True or False:* A number of individuals who are diagnosed with a genetic condition have no family history of the condition.
  - a) True
  - b) False
- 9) *True or False:* Some genetic conditions can only be passed on to children by their mothers and not their fathers.
  - a) True
  - b) False
- 10) Uncontrolled diabetes during pregnancy may lead to which of the following?
  - a) An increased risk of birth defects such as neural tube defects
  - b) An increased risk of complications during birth
  - c) Having a baby with an increased birth weight (greater than 9 lbs.)
  - d) All of the above
  - e) b & c
- 11) What is the chance that an individual who has an autosomal recessive condition will have a child with the same condition?
  - a) 0%
  - b) 25%
  - c) 50%
  - d) 100%
  - e) Cannot be determined from the information provided
- 12) Which of the following is/are **true** about changes (mutations) in DNA?
  - a) Changes in DNA can lead to cancer
  - b) Changes in DNA are **not** always passed on to children
  - c) Changes in DNA can be due to environmental exposures
  - d) All of the above
  - e) a & b

## Appendix H: Test (continued)

### The Role of Genetics in Nutrition

13) Which of the following is/are **true** about type 2 (adult onset) diabetes?

- a) Genetic testing is routinely performed for individuals with type 2 diabetes
- b) Most individuals with type 2 diabetes have inherited a single predisposing gene
- c) If an individual has a sibling with type 2 diabetes they are at an increased risk for developing type 2 diabetes
- d) All of the above are true
- e) b & c

14) Which of the following is/are **true** about autosomal dominant (AD) conditions?

- a) There is an equal chance of passing on the gene mutation responsible for an AD condition to both male and female offspring
- b) An individual who inherits an AD gene mutation sometimes will not have any of the characteristics or symptoms associated with the condition
- c) Family members with the same AD gene mutation can show variability in the types and/or severity of characteristics
- d) All of the above
- e) a & c

15) Which of the following is/are role(s) performed by genetic counselors?

- a) Assess the risk that an individual will have a genetic disorder based on family history or data from genetic studies
- b) Provide information about challenges or health problems the individual may experience based on a known genetic diagnosis
- c) Advise individuals on whether or not they should have children based on their genetic risk
- d) All of the above
- e) a & b

16) Which of the following is/are "red flag(s)" that indicate a disease may be due to a significant hereditary predisposition?

- a) Having more than one sibling in a family with the same condition (especially if it is a rare condition)
- b) Individuals with a significantly earlier age of onset than is usually seen in the general population
- c) Multiple generations of family members affected
- d) All of the above
- e) a & c

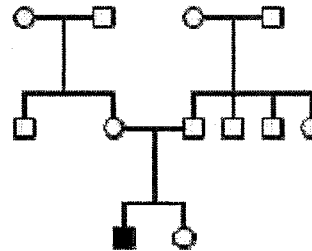
17) The incidence of type 2 diabetes is increasing in western countries because?

- a) Levels of toxins in the environment that contribute to type 2 diabetes are increasing
- b) Genetic mutations that cause diabetes are becoming more common
- c) Type 2 diabetes is being diagnosed more often due to better diagnostic testing
- d) The incidence of obesity is increasing
- e) None of the above

18) Which of the following (if any) has been shown to **decrease** the risk of certain birth defects if taken throughout the entire first trimester of pregnancy?

- a) vitamin A
- b) vitamin C
- c) folic acid
- d) zinc
- e) none of the above

19) In the pedigree below, what might be the underlying cause of the shaded individual's disease?



- a) His condition was due to a new dominant mutation in a gene
- b) His parents are each carriers of the same autosomal recessive condition and both passed their gene mutation on to him
- c) The condition is due to both genetic susceptibility and environmental factors
- d) All of the above
- e) None of the above

20) Which of the following is/are **true** about the role of DNA.

- a) It encodes the information for making *lipids*
- b) It encodes the information for making *proteins*
- c) It encodes the information for making *carbohydrates*
- d) All of the above
- e) None of the above

## Appendix I: Confidence and likelihood ratings for genetic related services

<b>Section I – Professional Skills</b>				
As a health care professional you may be asked to perform a variety of tasks. Please indicate:				
<p><b>A.</b> How likely you think it is you will be asked to perform this task in the career you are presently training for. Please circle a single number for each task.</p> <p><b>B.</b> How confident you are/would be in your ability to perform each task if you were asked to do so. Circle a single number for each task regardless of whether you have done it before or whether you think you might be asked to do it at some point in your career.</p>				
	<p><b>A) How likely is it that you will be asked to perform this task?</b></p>			
	<p><b>B) How confident are you in your ability to perform each task?</b></p>			
	<b>NOT</b>	<b>VERY</b>	<b>LOW</b>	<b>HIGH</b>
	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
a) Elicit and record genetic information when obtaining a family medical history	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
b) Discuss the genetic basis of disorders/conditions with your patients	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
c) Discuss your patients' genetic risks for common diseases such as diabetes and heart disease	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
d) Correct misconceptions about genetic disorders	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
e) Identify patients who would benefit from genetic counseling	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
f) Make appropriate referrals for genetic counseling	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
g) Make referrals for psychological counseling related to genetic issues	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
h) Provide guidance to patients with genetic disorders about what impact the genetic condition may have on their future	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
i) Provide counseling to patients making decisions about whether to have genetic testing	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
j) Provide psychological counseling related to coping with a newly diagnosed genetic disorder or test result	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
k) Obtain written informed consent to release genetic information to third parties	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5
l) Find and understand literature on genetic / nutrition related research	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5	1 2 3 4 5

## Appendix J: Genetic topics of importance

<b>Section II – Topics of Importance</b>					
How important do you think an understanding of the following topics will be to the career you are presently training for? <b>Please circle a single number for each topic.</b>					
	1	2	3	4	5
	NOT important				VERY important
a) Human genetics terminology	1	2	3	4	5
b) Inheritance patterns	1	2	3	4	5
c) Metabolic disorders	1	2	3	4	5
d) The genetic counseling process	1	2	3	4	5
e) Identifying patients who would benefit from genetic counseling, and/or genetic testing	1	2	3	4	5
f) Ethical, legal, and social implications of genetic testing	1	2	3	4	5
g) New treatments for genetic disorders	1	2	3	4	5
h) Importance of family history in estimating the likelihood that a person will develop a disease	1	2	3	4	5
i) Identifying other family members who may benefit from dietary interventions	1	2	3	4	5
j) Resources available to patients seeking genetic information	1	2	3	4	5
k) Genetically modified foods	1	2	3	4	5
l) Gene-diet interactions	1	2	3	4	5
m) Genetic influences on nutrition requirements	1	2	3	4	5
n) Genetics of common diseases (i.e. heart disease and diabetes)	1	2	3	4	5
o) Privacy and confidentiality in releasing genetic information	1	2	3	4	5
p) Communicating genetic information to patients	1	2	3	4	5
q) Helping patients cope with a genetic diagnosis	1	2	3	4	5
OTHER topics related to genetics and nutrition that are of interest or importance (please list)					
_____					
_____					

## Appendix K: Evaluation of intervention

### Section III – Evaluation of Genetic Educational Strategies

Please give us your opinion of the genetics content of this course. Your comments will help us improve how genetics is integrated into the nutrition curriculum in the future. Please circle the number that corresponds with your level of agreement with each statement.

1 = strongly agree, 2 = agree, 3 = neutral, 4 = disagree, and 5 = strongly disagree

INTEGRATING GENETICS INTO THE CURRICULUM...	Agree	Disagree
This course was an ideal place to incorporate genetics topics	1 2 3 4 5	
Genetics is a valuable and important subject for my future career	1 2 3 4 5	
Genetics should be integrated into multiple courses	1 2 3 4 5	
Because of this class, I am interested in learning more about genetics	1 2 3 4 5	

THE WEB-BASED TUTORIAL	Agree	Disagree
Helped me see the relevance of genetics to my future career	1 2 3 4 5	
Made the genetic information interesting	1 2 3 4 5	
Helped me understand principles of basic genetics	1 2 3 4 5	
Is an enjoyable way to learn genetics	1 2 3 4 5	
Helped me apply the genetic information to real-life situations	1 2 3 4 5	
Was written at a level that I could understand	1 2 3 4 5	
Was easy to use	1 2 3 4 5	

Did you do the web-based tutorial assignment? YES ? NO ?

Did you spend time looking at any of the links in the tutorial? YES ? NO ?

How long did you spend on the website? (Please include time it took you to do the assignment as well as time you spent browsing connecting sites.) \_\_\_\_\_ minutes or hours?

What did you enjoy most about the tutorial? Why?

\_\_\_\_\_

What was least enjoyable about the tutorial? Why?

\_\_\_\_\_

## Appendix K: Evaluation of intervention (continued)

CLASS PRESENTATION AND SPEAKER	Agree	Disagree
The presentation was well organized	1 2 3 4 5	
The presentation was enjoyable	1 2 3 4 5	
The presentation was an effective method for learning genetics	1 2 3 4 5	
The speaker was knowledgeable about the subject of genetics	1 2 3 4 5	
The speaker was clear and easy to understand	1 2 3 4 5	

THE USE OF CASE SCENARIOS DURING THE CLASS PRESENTATION...	Agree	Disagree
Helped me see the relevance of genetics to my future career	1 2 3 4 5	
Made the genetic information interesting	1 2 3 4 5	
Helped me understand principles of basic genetics	1 2 3 4 5	
Is an enjoyable way to learn genetics	1 2 3 4 5	
Helped me apply the genetic information to real-life situations	1 2 3 4 5	
Were written and presented at a level that I could understand	1 2 3 4 5	
Was an effective method for learning genetics	1 2 3 4 5	

What did you enjoy most about the presentation? Why?

\_\_\_\_\_

What was least enjoyable about the presentation? Why?

\_\_\_\_\_

What would you suggest that could improve the integration of genetics into the curriculum?

\_\_\_\_\_

Other comments or suggestions \_\_\_\_\_

## Appendix L: Demographic questions

### The Role of Genetics in Nutrition

Please fill in the following spaces with your four-digit identification number as described in the consent form . \_\_\_\_\_

*By completing this questionnaire you agree to have your answers used as part of the study.*

To answer the following questions, please circle the letter or check the box that best describe your response. Please provide *only one answer* to each question.

#### Section I - Education Information

1. What is your present field of study?
  - a. Nursing
  - b. Nutrition/ Dietetics
  - c. Other (please specify) \_\_\_\_\_
  
2. At what point are you in your training for this field of study?
 

a. College Freshman	e. Graduate school
b. College Sophomore	f. Internship
c. College Junior	g. Both Graduate school and internship
d. College Senior	h. Other (please specify) _____
  
3. Please list any other previous degrees, training, or careers \_\_\_\_\_
  
4. How much formal education have you had in genetics?

Please check yes or no for each	YES	NO
a. Genetics was covered in my high school biology class	<input type="checkbox"/>	<input type="checkbox"/>
b. I took a class on genetics in high school	<input type="checkbox"/>	<input type="checkbox"/>
c. Genetics is/was covered in one or more of my undergraduate courses	<input type="checkbox"/>	<input type="checkbox"/>
d. I have taken or am presently enrolled in a college course on genetics	<input type="checkbox"/>	<input type="checkbox"/>
e. I have a bachelor's degree in biology	<input type="checkbox"/>	<input type="checkbox"/>
f. I have a bachelor's degree in genetics	<input type="checkbox"/>	<input type="checkbox"/>
g. I have no formal genetics education	<input type="checkbox"/>	<input type="checkbox"/>

5. Have you ever attended a seminar/workshop/non-credit course having to do with genetics?  
     **Yes**            **No**

If yes, please list three topics that were covered in the presentation.

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

#### Section II - Demographic Information

1. Please write your present age: \_\_\_\_\_
  
2. Gender: male            female