The Genetic Literacy Project: Genetics Education Interventions for Asian American Prenatal Patients

Presenters:
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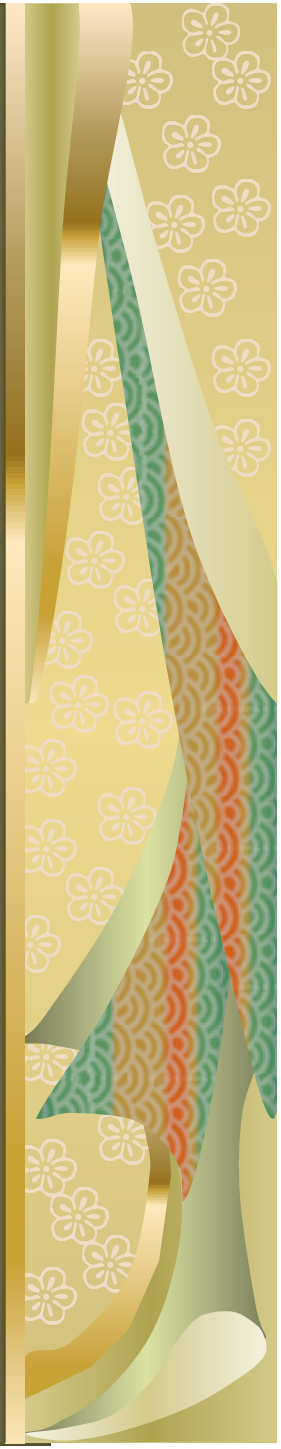
Charles B. Wang Community Health Center, Inc.

Presentation Objectives

- Introduce Charles B. Wang Community Health Center (CBWCHC) History and Background
- Describe Genetic Literacy Project Background, Goals and Activities
  - Genetic brochures
  - Pre-counseling workshops
- Describe Genetic Literacy Project Replication Process
- Share Genetic Literacy Project Evaluation Results



About CBWCHC

- Federally qualified non-profit community health center in NYC
- Started in 1971 to provide primary healthcare services to the Asian American community

Services

Internal Medicine	Health Education
Women's Health	Social Work
Pediatrics	Mental Health
Dental	Facilitated Enrollment

Mission

Be a leader in providing quality, culturally relevant and affordable health care and education

Advocate on behalf of the health and social needs of underserved Asian Americans

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Who CBWCHC Serves

The Health Center mostly serves the Asian American community in the New York City metropolitan area who are:

- Low-income
- Uninsured
- Under-insured

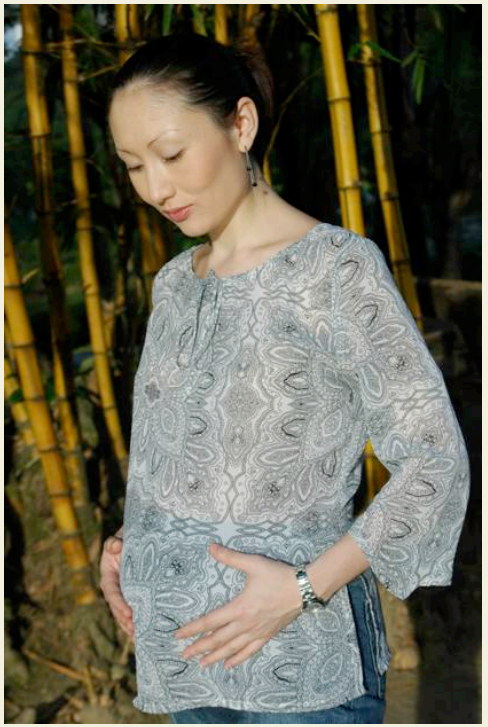
45% of households in Chinatown earned <$20,000/ year in 2000*

51.8% of Asian mothers who gave birth in NYC were on Medicaid in 1999*

Source: 2000 Census Data

Why is Genetics Education Necessary Among Asian Americans?

- Pregnant women and their partners need to be more informed of benefits of perinatal testing and genetic counseling
- Asian communities often left out due to cultural, socioeconomic and literacy barriers
- In North America, over 50% of thalassemia patients are Asian[1]
- 5.3% of all Asian mothers in New York City receive prenatal care either late or not at all, compared to 2.6% of Non-Hispanic White mothers[2]
- ~17% Asian Americans in the United States lack health insurance, compared to ~10% Non-Hispanic Whites.[3]



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[1] Vichinsky Changes in the Epidemiology of Thalassemia in North America: A New Minority Disease. PEDIATRICS Vol. 116 No. 6 December 2005, pp. e818-e825

[2]Bureau of Vital Statistics data compiled by Bureau of Maternal, Infant and Reproductive Health, New York City Department of Health and Mental Hygiene, February, 2009.

3 US Census Bureau http://www.census.gov/prod/2008pubs/p60-235.pdf

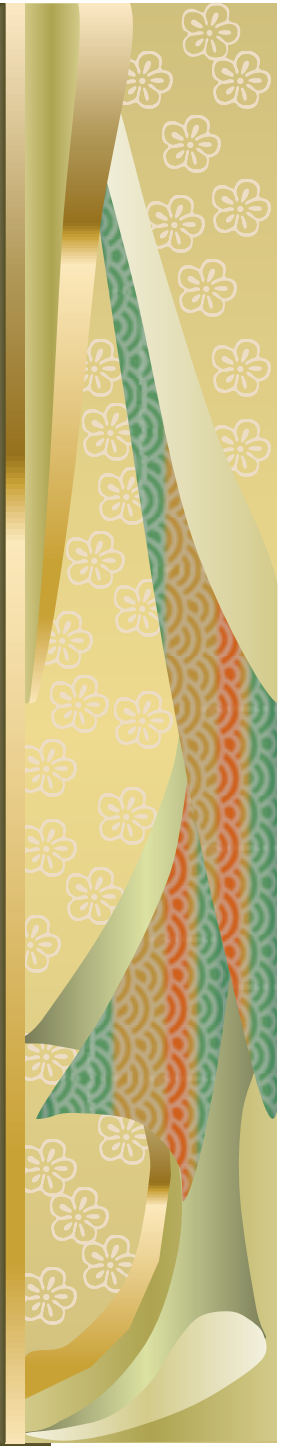
Project Goals & Objectives

- **Increase genetic literacy and access to genetic services among Asian American pregnant women and women of reproductive age in NYC**
- **Use a community-based participatory approach**
- **Share and disseminate information with other Asian communities through partnerships with organizations**

Why CBWCHC wants to your organization to replicate the Genetic Literacy Project:

- To introduce our program materials to other organizations for the benefit of the community/users.

- To receive feedback from other organizations on the Replication Tool Kit



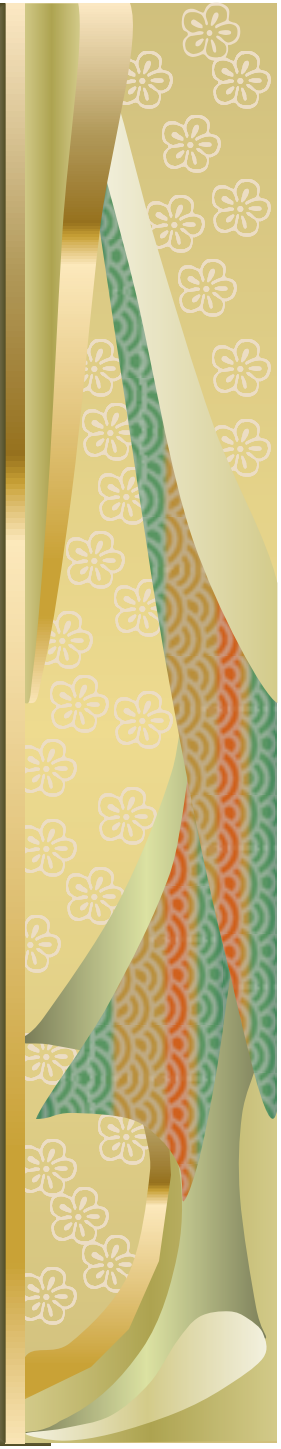
How will CBWCHC help your site replicate the Genetic Literacy Project:

- CBWCHC will recommend your organization to your local March of Dimes Foundation chapter to apply for funds to conduct the replication process.

- CBWCHC will provide your organization with a Replication Tool Kit that has all project materials, samples of evaluation tools, and reference information.

The Contents of the Replication Tool Kit:

- Introduction Video
- User's Guide
- Program Materials
- Evaluation Materials
  - Original Instruments used at CBWCHC



Replication Tool Kit:

- The introduction video will give an overview of project background and an example of a genetics 101 workshop

Replication tool Kit:

The User's Guide will provide information about the original program and how to implement either brochures, workshops or both.

USER'S GUIDE
Table of Contents

Replication Tool Kit:

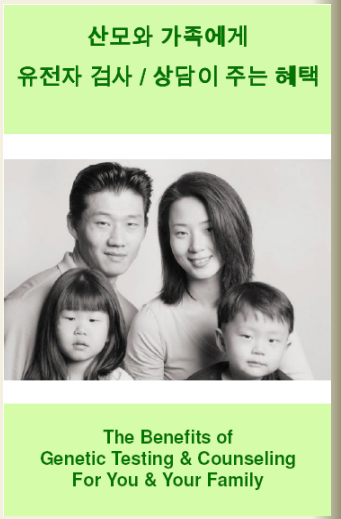
Program Materials

Brochures

- Amniocentesis: What it can do for you and your baby
- Maternal Serum-Triple Screen
- The Benefits of Genetic Testing & Counseling
- Thalassemia
- Family Health History

Replication Tool Kit:

Program Materials



- Amniocentesis, Maternal Serum-Triple Screen, The Benefits of Genetic Testing & Counseling, Family Health History, and Thalassemia are available in Chinese/English
- The Benefits of Genetic Testing & Counseling, and Amniocentesis are available in Korean/English
- Consumer tested with women of reproductive age at focus groups

Brochure Example:

Amniocentesis: how it can help you and your baby

Amniocentesis
How It Can Help You & Your Baby

You will learn:

- What amniocentesis is
- What happens during and after amniocentesis
- What the risks of amniocentesis are
- Who should get amniocentesis

What is Amniocentesis?

Amniocentesis is a test done between 4 to 5 months of pregnancy that can let you know if your baby has certain *birth defects* or some inherited health problems that run in your family.

Amniocentesis can find some but not every kind of problem in your baby. Even if your test results are normal, there is still a chance that your baby could have a mental or physical disorder.

What Happens During Amniocentesis?

A thin needle is put into your abdomen, which is used to take out a small amount of fluid that is around your baby. *Ultrasound* is used by the doctor to find an area where there is a lot of fluid far from the baby's body. A small amount of fluid is taken out and sent to a lab where tests will be done.

Amniocentesis is often done in a hospital. It takes about an hour and you can go home right after.

What is Ultrasound?
Ultrasound is a common pregnancy test. It uses sound waves to show a picture of the baby on a screen. The baby's body is measured and checked for major physical problems.

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产前抽羊水检查
对你和你胎儿的好处

这本小册子向你解释：

- 什么是抽羊水检查
- 抽羊水检查的过程
- 抽羊水检查有什么风险
- 谁需要作抽羊水检查

什么是抽羊水检查？

抽羊水检查是一种产前检查，可在怀孕 4 至 5 个月时进行，它可查出你胎儿是否患有某些先天性缺陷或查出您胎儿是否患有你们家族中存在的一些遗传性疾病。

抽羊水检查能查出您胎儿的某些健康问题，但并不是所有的健康问题都能查出来，即使其检查结果是正常的，胎儿仍有可能存在身体或心智方面的异常。

抽羊水检查的过程

利用一根细的穿刺针穿入您的肚皮，目的是在胎儿的周围抽出少量羊水，医生利用超声波找出一个羊水多、又远离胎儿的部位，抽出少量羊水，然后寄到化验公司进行检测。

抽羊水检查通常在医院进行，大约需要一个小时。检查完毕孕妇就可以回家。

什么是超声波检查？

超声波检查是怀孕期间一种常见的检查。
是利用声波在荧光屏上显示母体内胎儿的影像，用于测量胎儿的大小及检查胎儿身体的主要问题。

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Brochure Example:

Amniocentesis: how it can help you and your baby

What Kind of Problems Can Amniocentesis Find?

Once the fluid is taken out of your womb special tests are done to look for problems in your baby. The chart below shows what the tests look for:

1) Alpha-fetoprotein (AFP) Test
AFP is a substance made by the baby. The amount of AFP in your fluid is measured to look for birth defects.

Test Results—What They Mean
If your AFP levels are higher than normal, it is a sign that your baby may have physical problems such as *open neural tube defects*, which are physical problems in the baby's brain and spinal cord.

2) Chromosome Test
Chromosomes from your baby's skin cells found in the fluid are looked at to see if their shape and number are normal.

Test Results—What They Mean
If the shape and number of chromosomes are abnormal, it may be a sign of *Down Syndrome* or other problems in your baby.

Words to Know

Birth defect: A physical or mental problem that appears in the baby at birth or during early childhood. It can be caused by abnormal genes passed on to the baby from the parents, or by injury or infection.

Chromosomes: Structures inside cells that carry genes. We have 46 chromosomes (arranged in 23 pairs).

Down Syndrome: A genetic disorder that causes slow mental development and physical problems. Pregnant women who are age 35 and over have a higher risk of giving birth to children with Down Syndrome.

Genes: Genes are the units of inheritance. They are passed on from parents to child. They give information on how your body grows and functions. Genes determine features like height, eye color, hair color and even some types of illnesses.

抽羊水检查可以查出什么健康问题?

羊水从子宫抽出后，通过特殊的化验检测胎儿是否存在健康方面的问题。化验主要检测下列内容：

1. **甲胎蛋白(AFP) 的检查**
   甲胎蛋白是由胎儿产生的一种物质，其含量的高低可用来检测胎儿是否有某些先天性缺陷。
   检查结果的意义： 如果羊水中甲胎蛋白含量比正常高，这意味着胎儿可能存在身体方面的问题，例如神经管缺陷：即胎儿的脑及脊椎神经出现了问题。
2. **染色体的检查：** 从羊水中找出胎儿皮肤细胞可分析染色体的形状及数量是否正常。
   检查结果的意义： 如果染色体的形状和数量不正常， 胎儿可能患有唐氏综合症或其他健康问题。

词汇解释

先天缺陷： 婴儿在出生时或童年的早期出现身体或精神方面的问题。它可能是由于父母把不正常的基因传递给婴儿，或受伤或感染引起。

染色体: 细胞内携带基因的物质，我们每个人有 46 条染色 体，配成 23 对。

唐氏综合症： 是遗传方面的疾病，它导致智力发育障碍及身体方面的问题。年龄三十五岁或以上的孕妇，生下唐氏综合症婴儿的风险较高。

基因： 基因是遗传的单位。它们是由父母传递给孩子。它们决定人体的生长发育及其功能，基因决定人的特征，例如身高，眼睛、头发的颜色，甚至某种疾病。

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Brochure Example:

Amniocentesis: how it can help you and your baby

Should You Get Amniocentesis?

If you are pregnant and said "yes" to any of the questions below, you should think about amniocentesis.

- ☐ Will you be 35 years old or older when the baby is born?
- ☐ Have you already had a baby with a birth defect?
- ☐ Is there a history of genetic disorders in the family?
- ☐ Have you had more than two miscarriages?
- ☐ Have you had an abnormal result from blood tests done earlier in the pregnancy?
- ☐ Have you had an ultrasound that shows a possible inherited problem in the baby?

What Happens After Amniocentesis

After the test, take it easy. Rest and do not do any hard physical activity for one to two days. Your doctor will give you specific advice on what to do.

What if the Test Results Are Not Normal?

If your test results are not normal, your doctor may refer you to a *genetic counselor*.

A genetic counselor is a trained expert in medical genetics who works with people who may be at risk for a genetic disorder or an abnormal pregnancy. The genetic counselor can explain the meaning of the test results and discuss testing or pregnancy management options. The genetic counselor can give you information to help you make informed decisions about your pregnancy.

Risks of Amniocentesis

After amniocentesis, most women will have minor cramps for a short time but this is common. There is a very small chance of complications and miscarriage. If you have fever, bleeding from your vagina, pain, or other unusual symptoms, see a doctor right away.

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谁需要进行抽羊水检查？

以下的孕妇，应考虑接受抽羊水检查：

- 当婴儿出生时，孕妇年龄达到35岁或以上
- 已经生过一个有先天性缺陷的孩子
- 家族中有人有遗传性疾病
- 曾经有自然流产两次以上
- 怀孕早期抽血检查结果不正常
- 超声波检查时，发现胎儿可能有遗传性问题

抽羊水检查后应该注意什么？

抽羊水检查后，你需要放松和休息。一两天内避免重体力活动。你的医生会给你更多详细的建议。

如果检查结果不正常，我要做些什么？

如果检查结果不正常，你的医生会转介你去见遗传学顾问。遗传学顾问是经过医学遗传学训练的专业人士，帮助有基因异常风险的人和怀孕不正常的孕妇提供服务，他会向你解释检查结果，进一步的检查以及对怀孕的选择。遗传学顾问会提供信息，来帮助你作出决定，如何处理这次妊娠。

抽羊水检查的风险是什么？

抽羊水检查后，很多妇女会有轻度的腹部绞痛，这是很常见的。抽羊水检查后发生**并发症**和**流产**的机率很低。如果出现发热、阴道流血、疼痛或其它异常症状，你必须立即就医。

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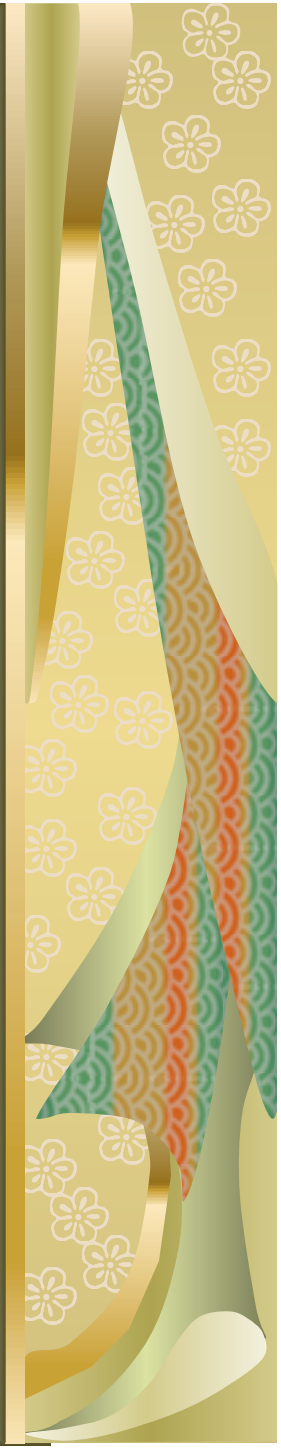
Replication Tool Kit:

Program Materials

- Workshops
  - Master Curriculums for Staff
    - Advanced Maternal Age
    - Thalassemia
    - Abnormal Maternal Serum Triple Screen Test
  - Workshop Curriculums for the community/users
    - Advanced Maternal Age
    - Thalassemia
    - Abnormal Maternal Serum Triple Screen Test

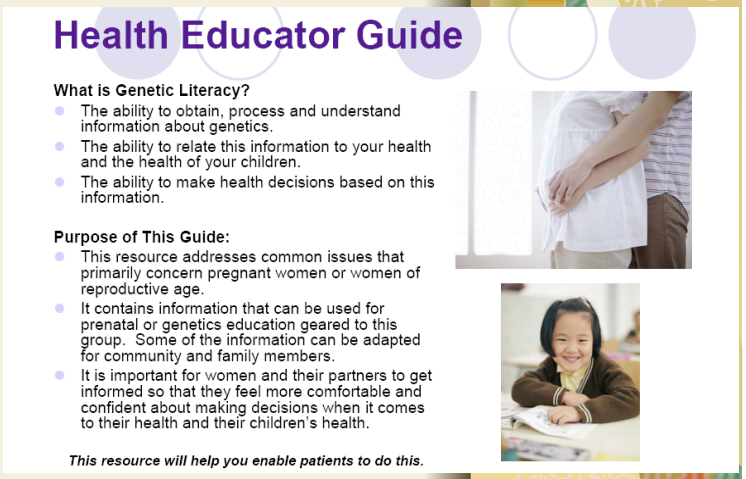


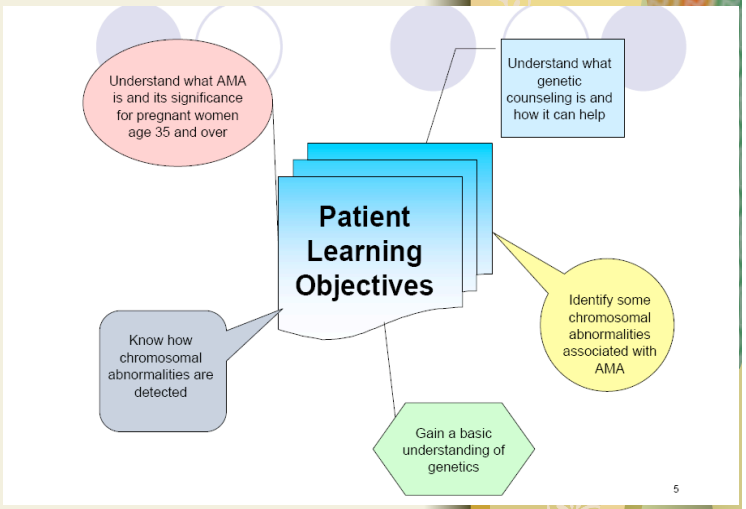
Replication Tool Kit:

Program Materials

Master Curriculum

- 1. Serve as a refresher about basic genetics, genetic disorders, prenatal tests and genetic counseling
- 2. Help the health educator plan for patient education sessions:
  - Key topics to cover
  - Key concepts and facts for the patient to know
  - Suggested talking points and activities





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Replication Tool Kit:

Program Materials

Master Curriculum for AMA

Resource Outline

- Topic: Advanced Maternal Age (AMA)
  - Why pregnant women age 35 and over should be aware
- Topic: Basic genetics
  - Chromosomes and genes
  - Heredity, i.e., passing on of chromosomes from parents to child
- **Topic: Common birth defects caused by chromosomal problems**
  - Down Syndrome, Trisomy 13, and Trisomy 18
- **Topic: Chance of a chromosomal abnormality at 35 years and older**
  - Chance or probability
  - How chance of chromosomal abnormalities increases with age
- **Topic: Options for women - what they can do**
  - Prenatal testing and amniocentesis
  - Genetic counseling
- **References for health educator**
  - FAQs
  - Glossary

Replication Tool Kit:

Program Materials

“Genetics 101” Workshop

- Patients who were of advanced maternal age, had thalassemia or an abnormal triple screen were referred to the genetic counselor
- Workshop is given by bilingual health educator
- Topic is based on patient’s reason for referral to the genetic counselor
- Provides patient with basic genetics concepts and information related to her reason for referral
- Patient workshops increase patients’ knowledge of genetics before seeing the genetic counselor at the health center

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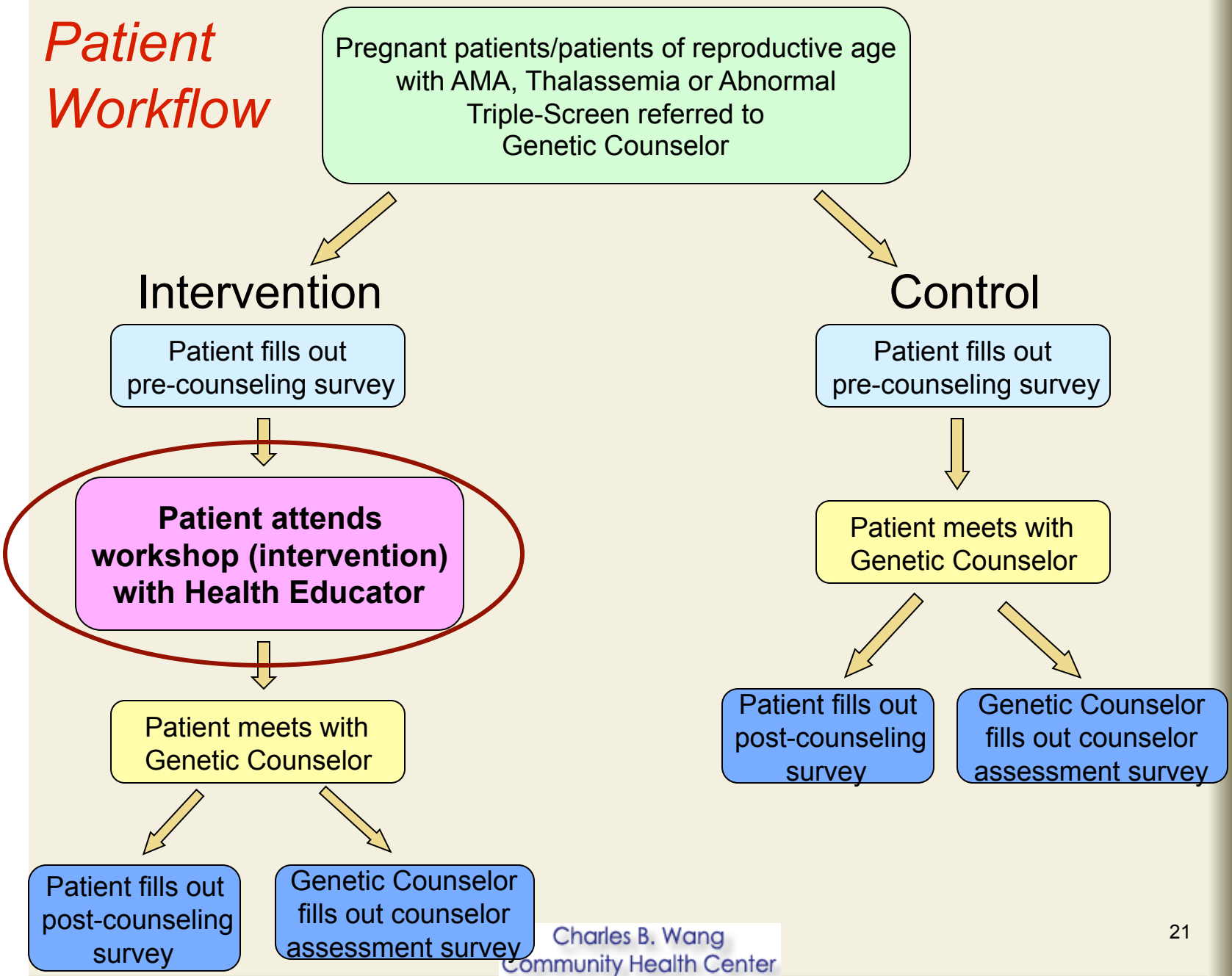
Patient Workflow



Replication Tool Kit:

Program Materials

Advanced Maternal Age Curriculum

- Genetic counseling for AMA
- Basic knowledge about chromosomes
- Chromosomes and genes
- Some common birth defects are caused by chromosomal problems.
- Down syndrome
- Trisomy 18
- The risk for a chromosomal disorder in women 35 years or older

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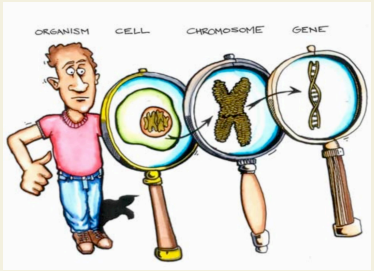
Replication Tool Kit:

Program Materials

Maternal Serum-Triple Screen Curriculum

- What is maternal serum-triple screen?
- What kind of disorders are tested for?
- Basic knowledge about chromosomes
- Chromosomes and genes
- Neural tube defects
- Down syndrome
- Trisomy 18
- How accurate are triple screen results?
- What happens after the triple screen?



Maternal serum – triple screen
孕婦血清三種物質檢驗

- **The Test Measures 3 Different Substances in the Mother's Blood**
- **這項檢查檢驗母體血內的三種不同的物質**
  - AFP ---甲胎蛋白
  - HCG ---絨毛膜促性腺激素
  - uE3 ---游離雌三醇

What happens after the triple screen?
檢查之後，你需要知道什麼？

- If your triple screen result is abnormal, your doctor may recommend more tests for you to take:
  - **Ultrasound**
  - **Amniocentesis**
- Your test results may show that your baby has a higher risk for one of the following birth defects:
  - Neural Tube Defects
  - Down Syndrome
  - Trisomy 18
- 如果你的檢查結果異常，你的醫生可能建議你作進一步的檢查，如：
  - **超聲波檢查**
  - **抽羊水檢查**
- 檢查結果可顯示你的胎兒有較高的風險患上以下先天性缺陷的其中一種。
  - 神經管缺陷
  - 唐氏綜合症
  - 18三體綜合症

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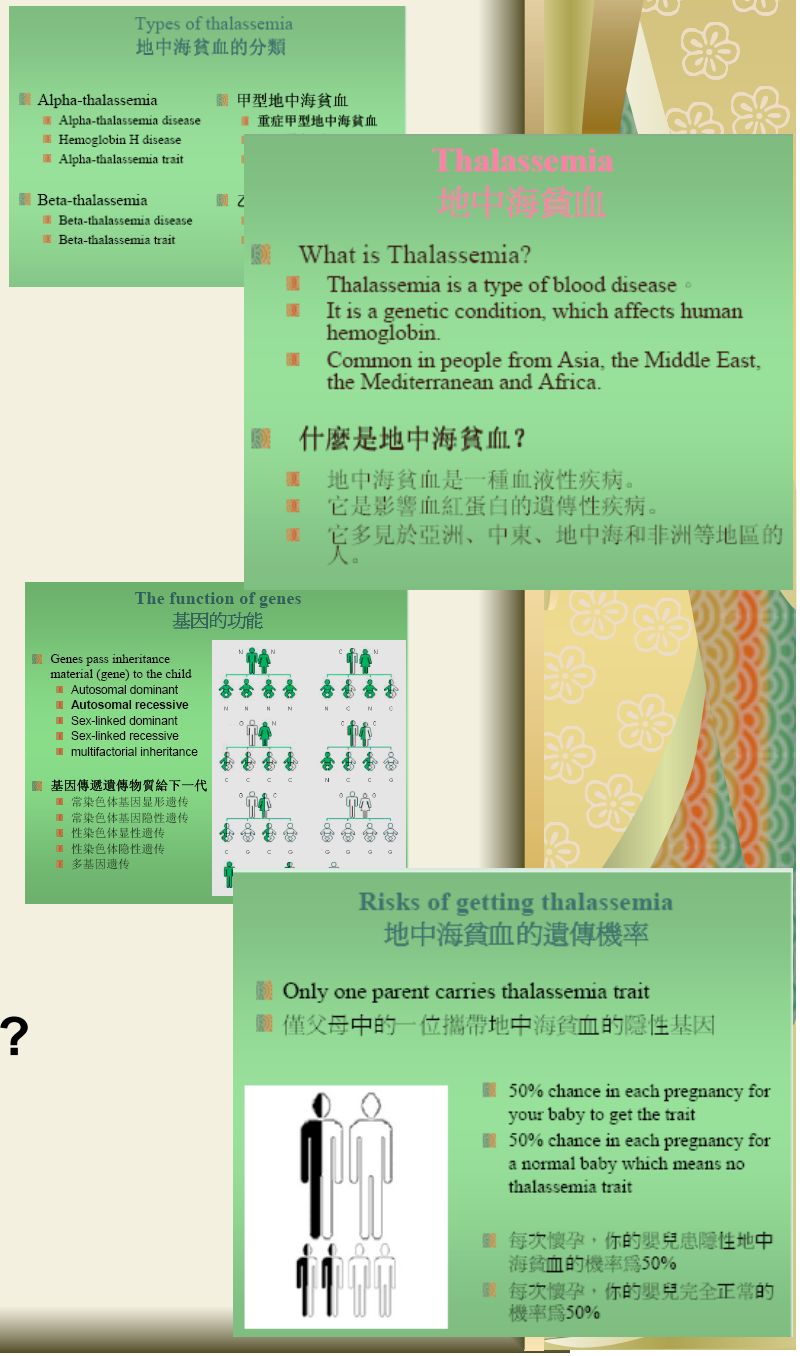
Replication Tool Kit:

Program Materials

Thalassemia

- What is thalassemia?
- Why is hemoglobin important?
- How do you get thalassemia?
- Basic knowledge about chromosomes
- Chromosomes and genes
- The function of genes
- Types of thalassemia
- How do you know you have it?
- Thalassemia and pregnancy
- Risks of getting thalassemia
- What do I do if I carry thalassemia trait?



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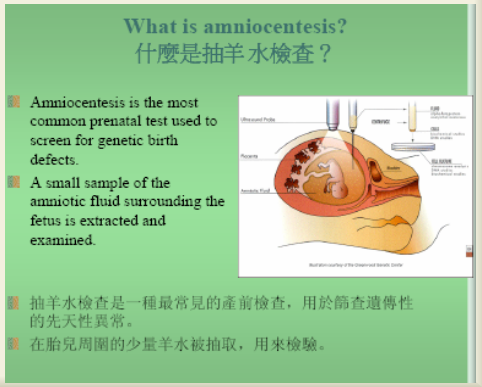
Replication Tool Kit:

Program Materials

Topics included in all 3 workshops

- What is amniocentesis?
- How is the test performed?
- What kinds of problems can amniocentesis detect?
- What are the risks of an amniocentesis?
- What do I do if the amniocentesis result is abnormal?
- Why is family history so important to your health?
- What is genetic counseling?
- Who should get genetic counseling?
- What can a genetic counselor do for you and your family?
- What happens after genetic counseling?



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Replication Tool Kit:

Workshop Evaluation

- The Replication Tool Kit also includes all evaluation materials used by CBWCHC to evaluate the effectiveness of the workshop.
  - Pre/post surveys
  - Genetic Counselor Assessment

- Evaluation analysis of “Genetics 101” workshop materials showed statistically significant positive outcomes for the users.

Evaluation of workshops: Methods-

- We compared **two cohorts** -- patients who received pre-counseling workshops (***Intervention Group***) vs. those who did not (***Control Group***).

- Data was collected from **June 1, 2009** to **November 20, 2009**. $10 Bakery cards were used as incentives to recruit patients.

- Data was collected using short pre and post workshop questionnaires administered to all eligible and consenting patients. **The questionnaires addressed the following areas:**

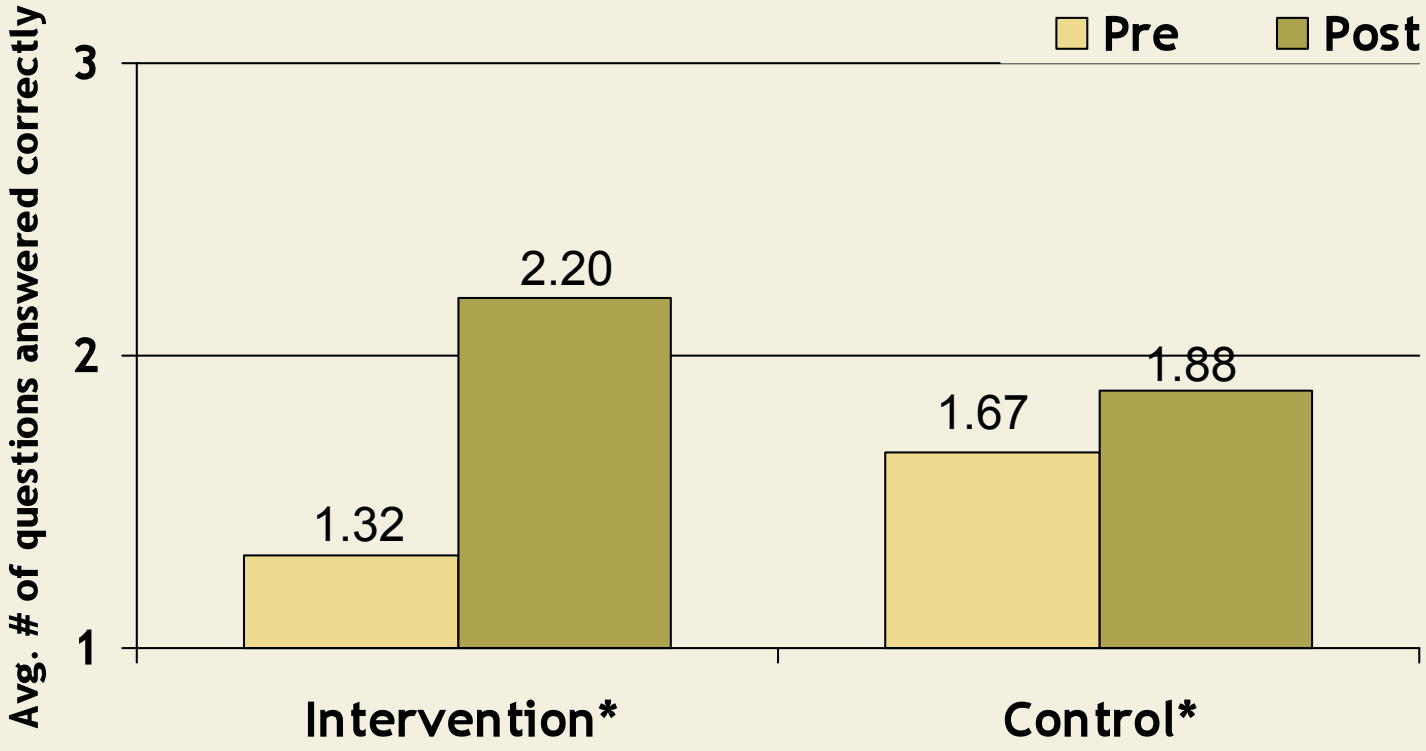
  - Patient knowledge/awareness of basic genetic concepts and their importance on health
  - Patient attitude toward genetic counseling
  - Patient self-efficacy regarding genetic counseling and testing
  - Patient satisfaction with the genetic counseling
  - Quality of communication between the patient and the genetic counselor and health educator

Workshop Findings:

Change in Knowledge -

Reasons for seeing a genetic counselor

(N=86, intervention n =44, control n=42)



***Statistically significant difference ($p<0.05$) found between the pre and post surveys.**

The change in the intervention group was found to be statistically greater than that for the control group.

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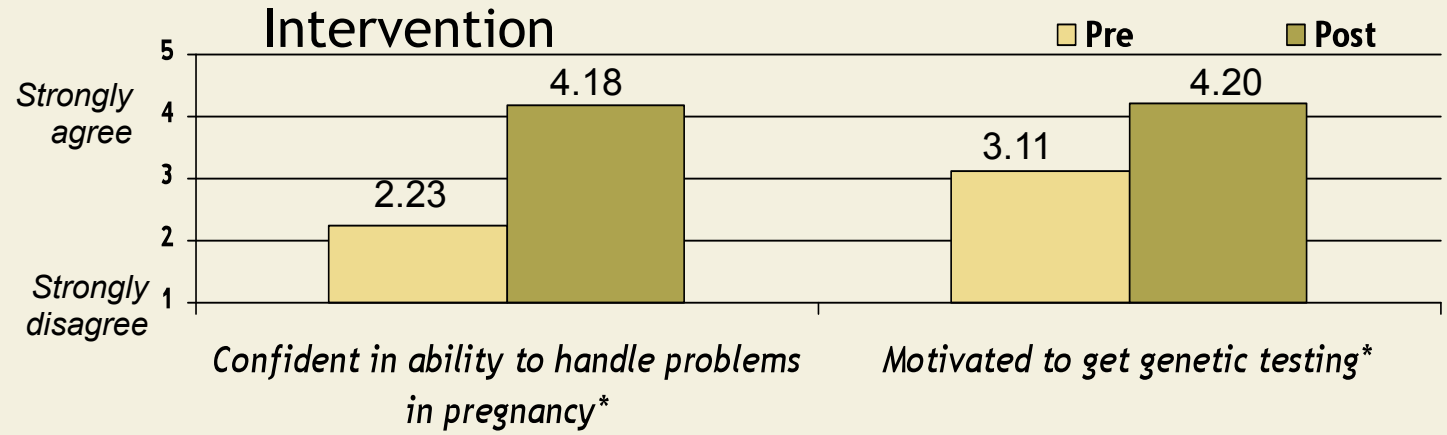
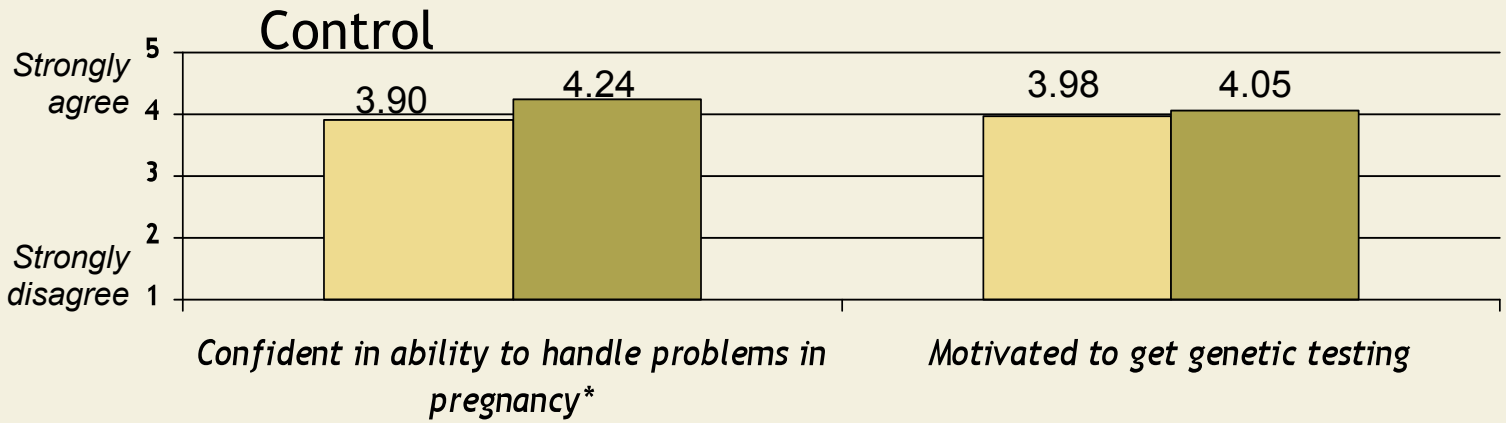
Workshop Findings:

Change in Self-Efficacy

Average Score (N=86, intervention n =44, control n=42)





***Statistically significant difference ($p<0.05$) found between the pre and post surveys for both intervention and control groups. However, the change in the intervention group was statistically greater than that in the control group for both categories.**

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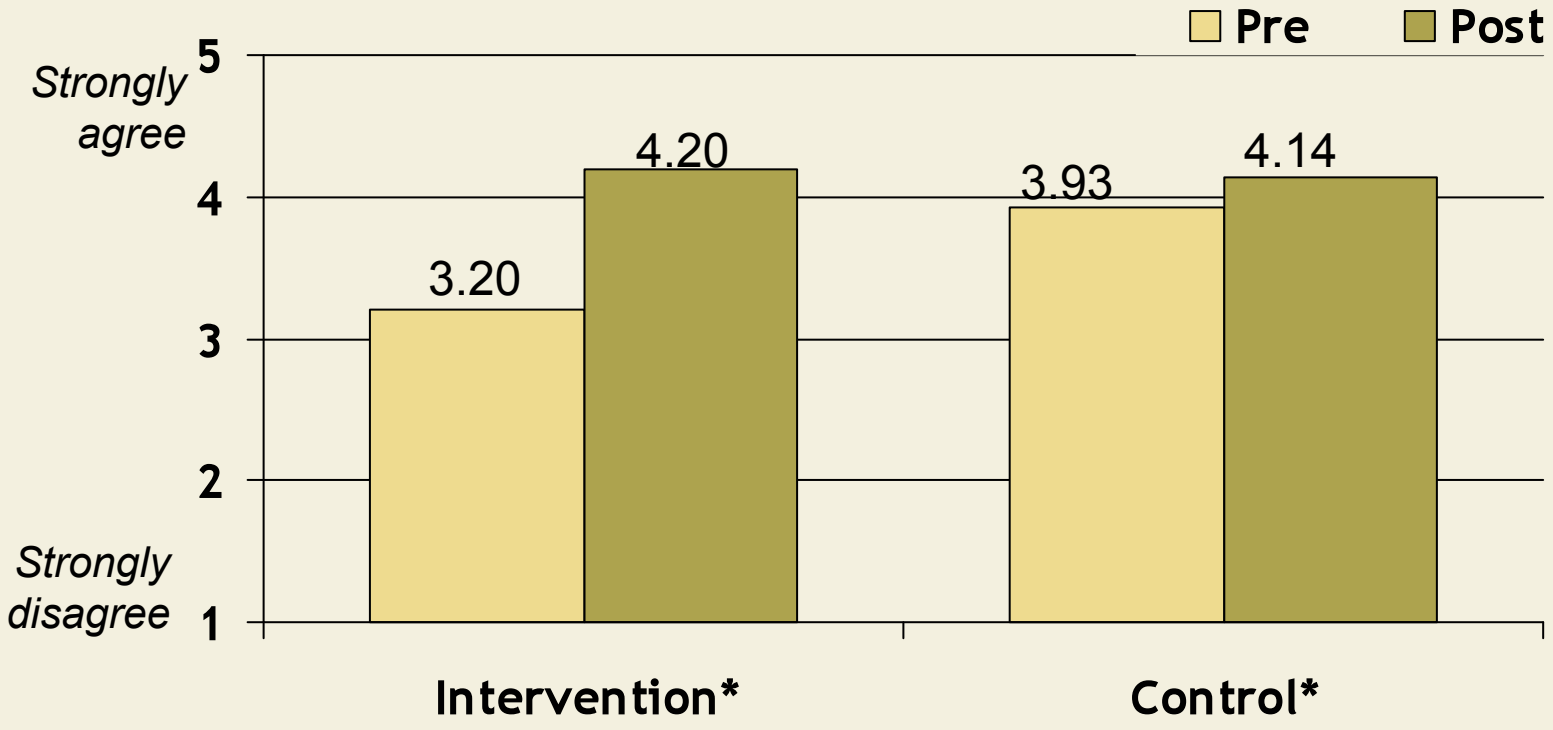
Workshop Findings:

Change in Attitude

Average Score (N=86, intervention n =44, control n=42)

Would consider seeing a genetic counselor in the future:



***Statistically significant difference ($p<0.05$) found between the pre and post surveys for both the intervention and control groups. The change in the intervention group was statistically greater than that in the control group.**

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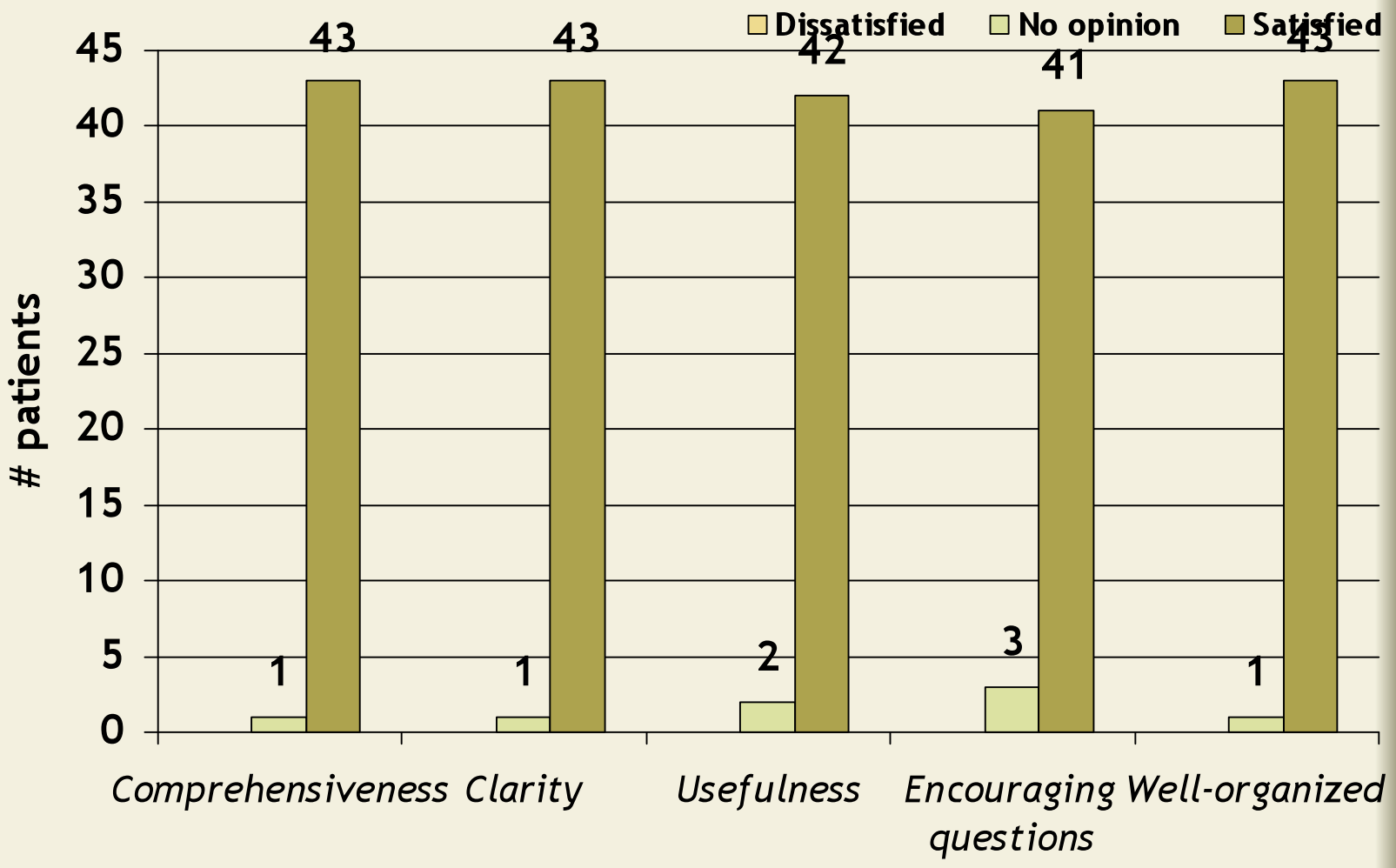
Workshop Findings:
Satisfaction with Intervention

(Intervention n =44)



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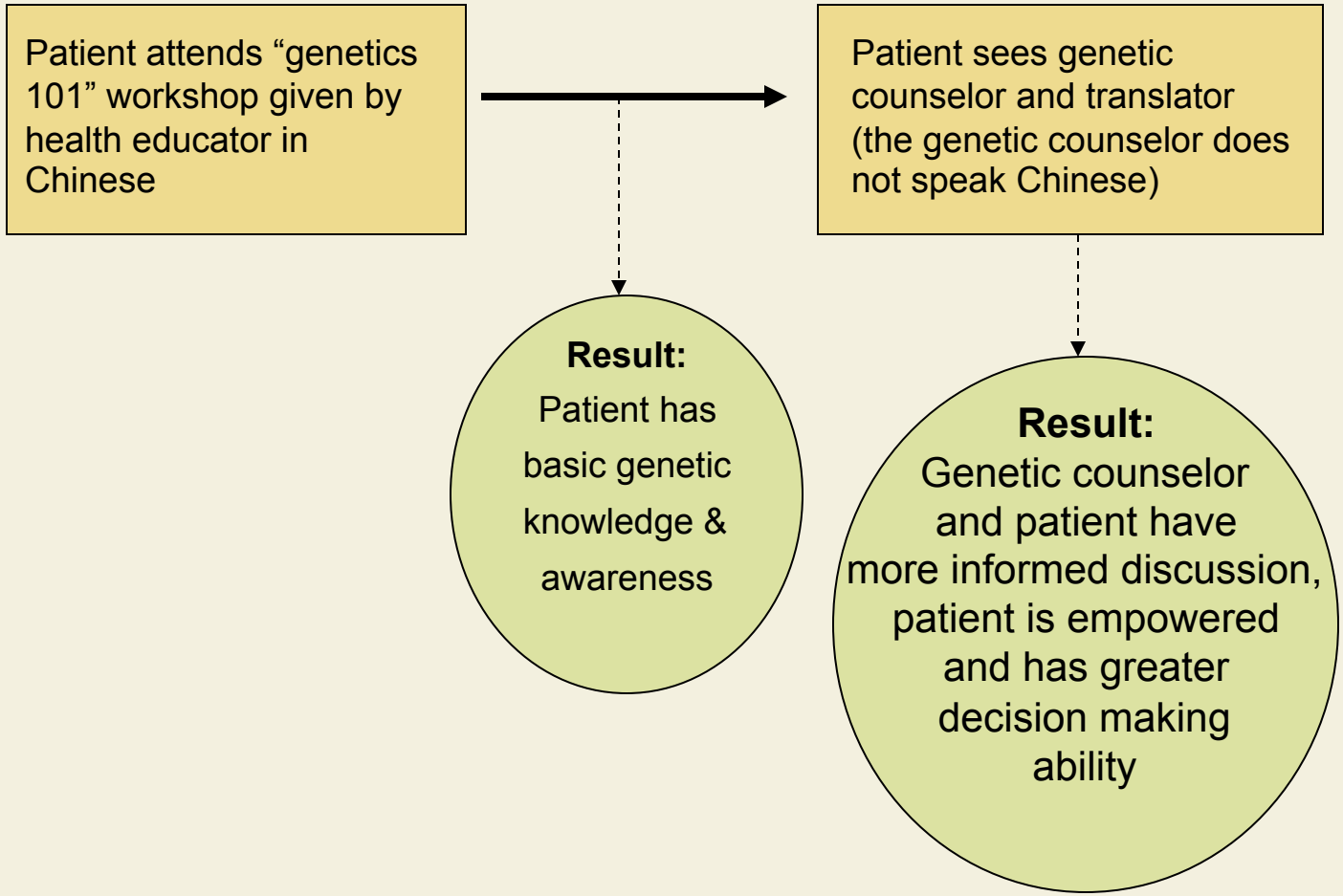
Workshop Findings:

Length of Genetic Counseling Appointment Time (N =26)

	Intervention n = 16	Control n = 10
Average Appt. Time (Minutes)	20.63	34.20
SD	5.06	4.98

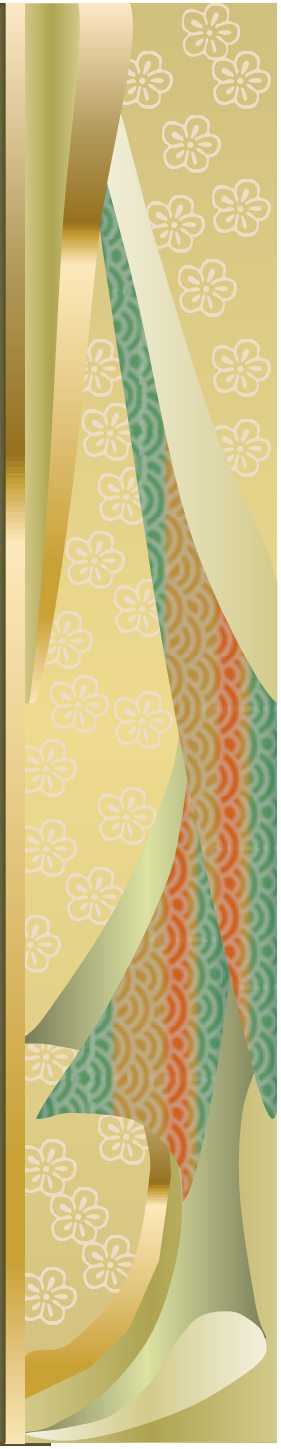
*Data was collected from CBWCHC's Electronic Medical Records system to assess the Genetic Counselor's appointment time.

Result Summary:



Conclusions

- Replication of the Genetic Literacy Project promises to benefit both the organization and the community
- CBWCHC will recommend the replication site for March of Dimes funding support
- CBWCHC will provide copies of the Replication Tool Kit for the Genetic Literacy Project to all interested organizations.
- Materials are culturally and linguistically appropriate
- Evaluation analysis showed promising findings for the effectiveness of the pre-counseling workshops



Special thanks to:

- The Association of Asian Pacific Community Health Organizations (AAPCHO) for coordinating and hosting Webinar.

- Women's Health Department at the Charles B. Wang Community Health Center.

- CGEN partners: March of Dimes, HRSA, Dominican Women's Development Center, University of Utah/ Utah Department of Health, Howard University, Julie Solomon, PhD, and Midwest Latino Health Research Center

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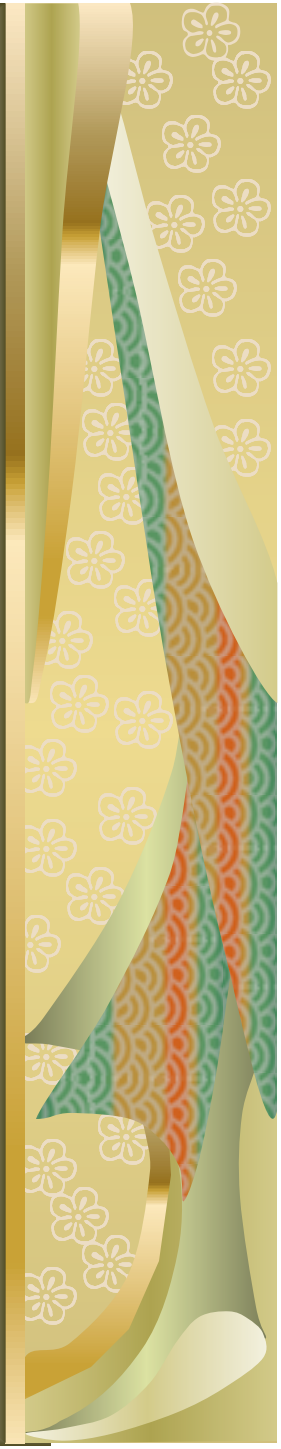

Thank you for your time!

If you have any questions, please contact Christine Chan at

(212)-966-0228 ext 227 or chchan@cbwchc.org

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