

# Perinatal Quality FOUNDATION

Genetic Education Modules (GEM)

# Perinatal Quality Foundation

## a 501C3 non-profit organization

**MISSION:** *“Improving the quality of obstetrical medical services by providing state of the art educational programs ...”*

2004: NTQR is a U.S. based NT credentialing program that has developed national consensus criteria for educational and exam content, proficiency evaluation, and epidemiologic monitoring.

2012: CLEAR trains persons performing transvaginal ultrasound cervical length measurement in pregnancy to adhere to standardized criteria for documentation of transvaginal ultrasound cervical length.

2013: FMC was created to promote a common understanding of EFM interpretation. The PQF credentialing exam combines both knowledge and judgment questions to assess interpretation of EFM in specific clinical situations.

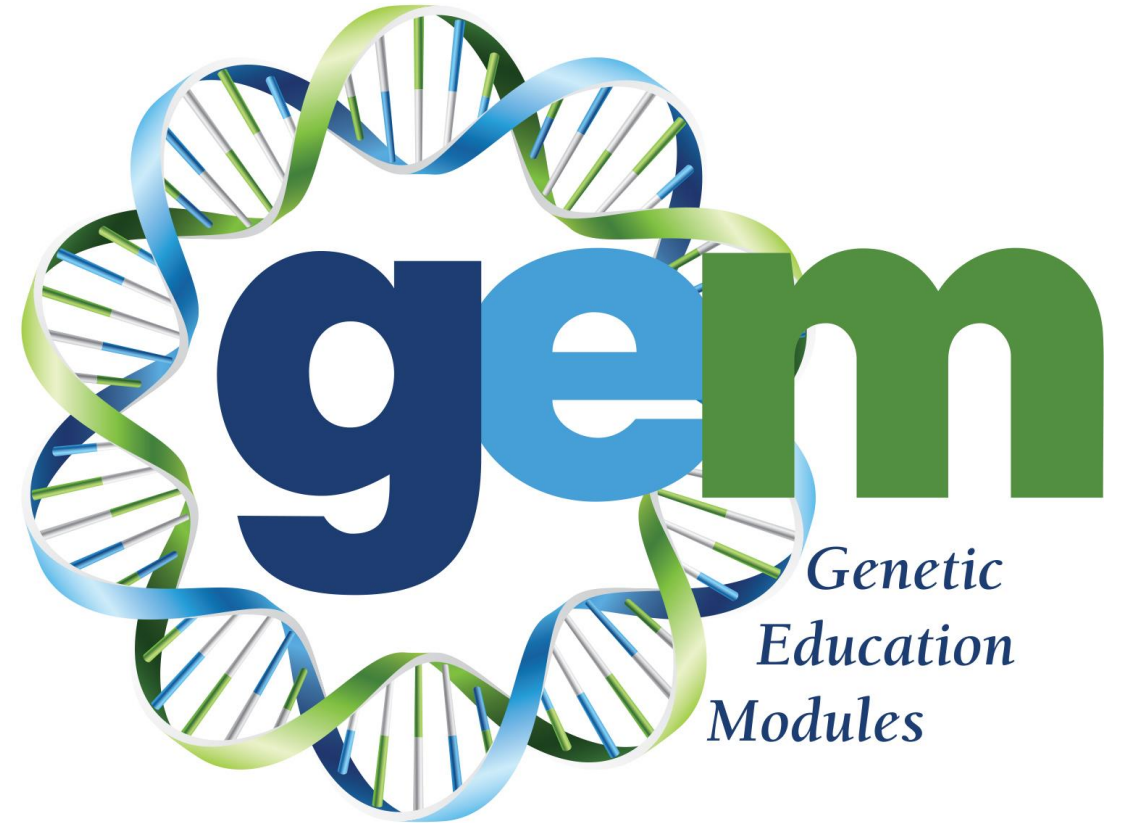
## 2016: GEM.Perinatalquality.org

Provides information about genetic testing commonly offered during pregnancy to clinicians, staff, and patients.

Provides videos, tools and resources for patient and healthcare provider and staff education.

Makes available a patient's *Discussion Planner* that documents education and may be used to facilitate communication between provider and patient.

GEM is web-based and can be accessed on any desktop computer, smart phone or tablets.



# PQF / California CDPH Partnership

- GEM will be available to 500 CDPH Providers
- Videos by leading MFM geneticists - Wapner, Norton, Dugoff
- Patient education tools and information
- Unlimited access from registration thru December 31, 2022 and longer as needed
- 3.5 hours of CME available to each provider

# Registration

Language: Spanish (Español) | Learn More | Help | Request Brochure | Webinar

**gem** Genetic Education Modules  
Resources for OB Providers and Women in Pregnancy

Sign In Register

Welcome to GEM  
Click on the Introductory Video below to Explore

Developed by leading physicians and genetic counselors, GEM is a comprehensive, unbiased educational website to help women navigate the complexities of genetic testing in pregnancy. From the comfort of home, women and their partners can review information and videos to help better understand the various tests offered during pregnancy. GEM helps answer important questions like, "What are my risk factors?" "What information is available to know about a pregnancy before birth" or "How much information do I want about my pregnancy?"

While most babies are born healthy, it is important to understand the options for obtaining genetic information about a pregnancy and baby's health. The site provides five interactive tools that can help women to decide which tests are best for them. GEM provides concise, accurate information necessary to help make a fact-based decision or help guide discussion about testing options with health care providers or family. Taking time to learn about the options for testing is the best way to make a plan for the pregnancy and the baby. There is no right or wrong answer about testing in pregnancy – just the one that is best for each person.

I am a Provider or Practice Personnel (Incl. California) | I am a Patient

Best for Providers, Practice Administrators, Faculty | Best for Patients

Click here to Register for Providers/Practice Personnel

Language: Spanish (Español) | Learn More | Help | Request Brochure | Webinar

**gem** Genetic Education Modules  
Resources for OB Providers and Women in Pregnancy

Sign In Register

Perinatal Quality Foundation  
GEM Q&A  
Dr. Karen Callen, Senior Partner  
Golden Gate Obstetrics & Gynecology

GEM provides an unparalleled patient-centered experience with web-based access to unbiased educational materials and interactive patient decision tools. Information is available on screening and diagnostic testing for common chromosomal conditions as well as cancer screening. These resources were created by prenatal genetics' thought leaders to empower each individual to make informed, educated, and value-based choices regarding the genetic testing strategy that is most consistent with their own preferences. Practices can demonstrate recommended care by providing unbiased and expert guidance. Patients can explore GEM outside of an office visit, leading to enhanced understanding, more nuanced discussions, and higher patient satisfaction.

- Reduces clinic time required for pre-test education
- Provides documentation of patient pre-test education
- Educates office staff to answer basic questions
- Provides unbiased and expert patient education about prenatal test options
- Provides layered content for all levels of health literacy
- Contains interactive tools to compare and contrast testing options
- Providers can earn CME, and Category 4 ABOG MCC credit

Provider (Incl. California) | Practice Personnel

Best for Providers with a subscription practice code | Best for Providers, Faculty & Practice Administrators to initiate a subscription

- GEM.perinatalquality.org
- Go to “Register”
- Pg 1: Clinician / Provider
- Pg 2: Clinician / Provider
- Use CDPH Subscription Practice Site Code = CDPH1234
- Save username / password for unlimited access

# PROVIDER CREDENTIAL and CME

Step	Status
Step 1. Complete Registration	<input checked="" type="checkbox"/> Completed: 04/05/2017
Step 2. Review Provider Material	<input checked="" type="checkbox"/> Completed: 04/05/2017 <a href="#">Access Provider Content</a>
Step 3. View Course	<input checked="" type="checkbox"/> Completed: 04/05/2017 <a href="#">View Course</a>
Step 4. Review Patient Material	<input checked="" type="checkbox"/> Completed: 04/05/2017 <a href="#">Access Patient Content</a>
Step 5. Pass Exam	<input checked="" type="checkbox"/> Completed: 04/20/2017 <a href="#">Exam Results</a>
Step 6. Complete CME Evaluation	<a href="#">Complete CME Evaluation</a>
Step 7. GEM Credentials	Not Complete
Step 8. Print CME Certificate	Not Complete
Step 9. Print Documentation of GEM Completion	Not Complete



# Video Course Lectures



# GEM Provider Module

Focuses on genetic testing education, non-directive counseling, how to handle abnormal results, and when to refer to a genetic counselor.



The carrier screening provider module has guides to choosing a panel and for counseling couples.

## Provider Module

Explaining prenatal testing can be difficult. Patients come from diverse backgrounds. Their decision-making regarding genetic testing may be influenced by a variety of factors including moral, religious, and cultural beliefs.



CLEAR COMMUNICATION

### Patient Experience

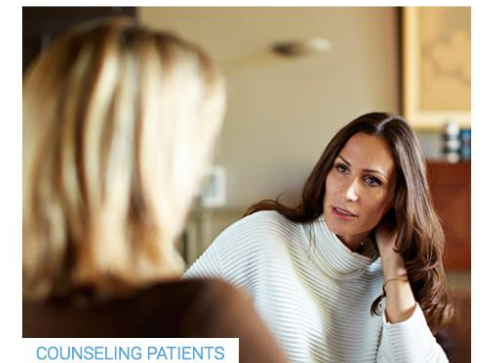
Explaining prenatal testing can be difficult.



UTILIZING RESOURCES

### When to Refer

Regardless of your breadth of knowledge, there are ti...



COUNSELING PATIENTS

### How to Handle Abnormal Results

Helping patient's make the best choices for them









# Provider and Patient Videos





- Videos are posted throughout the site and are available for review on one page as well.
- These videos can be found on the provider and patient pages and may be used as a common resource for education.

## TEST OPTIONS



 Prenatal cell-free DNA Screening 35 sec	 Chromosome Analysis 1 min	 Microarray Analysis. 38 sec	 Multiple Marker Screening. 47 sec
--	--	--	--

## PATIENT PERSPECTIVES

[See all >](#)

 Sarah explains how knowing information during pregnancy can help prepare older siblings. 23 sec	 Fatima talks about the importance of information changing her view. 16 sec	 Fatima talks about how information to compare options is helpful to her. 19 sec	 Carlie is empowered by getting information and making a plan. 28 sec
--	---	--	---

## PROVIDER VIDEOS

 An example of non-directive counseling. 1 min	 An example of shared decision-making. 1 min
---	---

# Patient Module

- The patient module provides information, tools, videos, a glossary and other resources that may be accessed prior to and throughout pregnancy.

Learn More: [Help](#) | [Request Brochure](#) | [Press Room](#) | [Webinar](#)

**gem**  
Genetic Education Modules  
Resources for OB Providers and Women in Pregnancy

[My Account](#) [Sign Out](#)

[Home](#) [Learn](#) [Decide](#) [The Tests](#) [Tools](#) [Videos](#) [Discussion Guide](#)

**Learn**  
What you need to know about Prenatal Genetic Testing  
Overview of genetic conditions and testing approaches  
[LEARN MORE](#)

**Decide**  
Making the decision that's right for You  
Learn about important factors to consider in deciding about testing.  
Find resources to help you get more information or make decisions.  
[LEARN MORE](#)

**Just the Basics:**  
A Short Introduction to GEM: a fast-track for patients who want to start with the basics  
[LEARN MORE](#)

When you're ready:  
[Learn about the different genetic testing options >](#)

# TESTING OPTIONS

## Screening Tests

- Prenatal Ultrasound
- Multiple Marker Screening
- Cell-free DNA Screening

## Diagnostic Tests

- Diagnostic Testing by CVS/Amniocentesis
- Chromosome Analysis
- MicroArray Analysis

## Genetic Carrier Screening Tests

## No Testing

### Screening Tests



#### Prenatal Ultrasound

One of the first tests available to you. Ultrasound has many uses, including confirming a due date, identifying twins, and looking for congenital anomalies.

[LEARN MORE](#)



#### Multiple Marker Screening

Traditional blood test screening to look for Down syndrome, trisomy 18 and open spina bifida. Doesn't tell for sure but doesn't increase the chance for miscarriage.

[LEARN MORE](#)

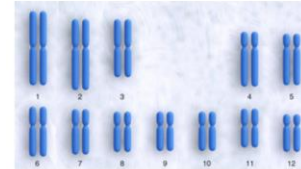


#### Cell-free DNA Screening

Newest, more effective prenatal blood test screen for Down syndrome, trisomy 18, trisomy 13 and sex chromosomes. Doesn't tell for sure but doesn't increase the chance for miscarriage.

[LEARN MORE](#)

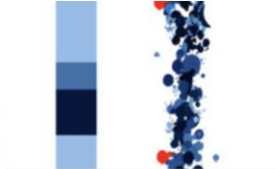
### Diagnostic Tests



#### Chromosome Analysis by CVS/Amniocentesis

Diagnostic testing that can tell for sure if a fetus has Down syndrome or other obvious chromosome conditions. Procedure to get cells to test has a small chance for miscarriage.

[LEARN MORE](#)



#### Microarray Analysis by CVS/Amniocentesis

Diagnostic testing that can tell for sure if a fetus has Down syndrome, other major chromosome conditions, or very small pieces of genetic material that are extra or missing. Procedure to get cells to test has a small chance for miscarriage.

[LEARN MORE](#)



#### Diagnostic Testing By Chorionic Villus Sampling (CVS)/Amniocentesis

Tissue for chromosome analysis and chromosomal microarray analysis(CMA) can be taken from the pregnancy through chorionic villus sampling (CVS) or amniocentesis. Some obstetricians perform these procedures in their offices. Other obstetric care providers refer their patients to Maternal-Fetal Medicine (MFM) specialists to discuss testing or have testing performed.

[LEARN MORE](#)

# Tools

User testing shows that the tools are unique and very popular with patients.



## Compare Tests

Choose two testing options to compare side by side

[LEARN MORE](#)



## Risk Profiler and Test Detection Tool

Displays the chance of an anomaly in your pregnancy AND how testing options differ in what each can find

[LEARN MORE](#)



## Testing at-a-Glance

Overview and comparison of testing options

[LEARN MORE](#)



## Decision Tool

10 questions to help you think about the testing option(s) that may be best for you

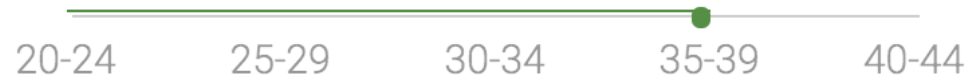
[LEARN MORE](#)

# Risk profiler & test detection tool

- Home
- Tests
- Tools**
- Videos
- Discussion Planner

## Risk Profiler and Test Detection Tool

Choose Your Age



**95%**  
**(9,487/10,000)**  
chance that pregnancy is NOT affected with the most common congenital anomalies.

**5%**  
**(513/10,000)**  
chance that pregnancy IS affected with the most common congenital anomalies.



Choose a test to see what kind of conditions can be detected with that test.

- ULTRASOUND\***
- MICROARRAY ANALYSIS\*\***
- CHROMOSOME ANALYSIS\*\***
- cfDNA\*\*\***
- MULTIPLE MARKER**

Genetic Condition	Chance out of 10,000 (%)	Detection (% identified by testing)
CONGENITAL ANOMALIES	200/10,000 (2.0%)	<ul style="list-style-type: none"> <li>70% (ULTRASOUND*)</li> <li>0% (MULTIPLE MARKER)</li> <li>0% (CHROMOSOME ANALYSIS**)</li> <li>0% (cfDNA***)</li> <li>0% (MICROARRAY ANALYSIS**)</li> </ul>
HEART DEFECTS	100/10,000 (1.0%)	<ul style="list-style-type: none"> <li>60% (ULTRASOUND*)</li> <li>0% (MULTIPLE MARKER)</li> <li>0% (CHROMOSOME ANALYSIS**)</li> <li>0% (cfDNA***)</li> <li>0% (MICROARRAY ANALYSIS**)</li> </ul>
MICRODELETION OR MICRODUPLICATION	100/10,000 (1.0%)	<ul style="list-style-type: none"> <li>99% (MICROARRAY ANALYSIS**)</li> <li>0% (ULTRASOUND*)</li> <li>0% (MULTIPLE MARKER)</li> <li>0% (CHROMOSOME ANALYSIS**)</li> <li>0% (cfDNA***)</li> </ul>
SEX CHROMOSOME CONDITION	38.8/10,000 (0.4%)	<ul style="list-style-type: none"> <li>99% (MICROARRAY ANALYSIS**)</li> <li>99% (CHROMOSOME ANALYSIS**)</li> <li>90% (cfDNA***)</li> <li>0% (ULTRASOUND*)</li> <li>0% (MULTIPLE MARKER)</li> </ul>
TRISOMY 21	53.8/10,000 (0.5%)	<ul style="list-style-type: none"> <li>50% (ULTRASOUND*)</li> <li>99% (MICROARRAY ANALYSIS**)</li> <li>99% (CHROMOSOME ANALYSIS**)</li> <li>99% (cfDNA***)</li> <li>92% (MULTIPLE MARKER)</li> </ul>
TRISOMY 18 or TRISOMY 13	20.1/10,000 (0.2%)	<ul style="list-style-type: none"> <li>90% (ULTRASOUND*)</li> <li>99% (MICROARRAY ANALYSIS**)</li> <li>99% (CHROMOSOME ANALYSIS**)</li> <li>91% (cfDNA***)</li> <li>90% (MULTIPLE MARKER)</li> </ul>


# Decision Tool

## Decision Tool

The statements below reflect personal values and preferences that individuals have indicated were meaningful in making a decision about prenatal genetic testing. Read each statement and consider how you feel about each one. Below each of the following 10 statements, select whether you Agree, Not Sure, or Disagree. After you have selected a response for each statement, click the Submit button located just below question number 10.

- 1 I want to know if my pregnancy is affected with a genetic condition or congenital anomaly.
- 2 I want the most information available about my baby and my pregnancy, even if there is a small risk associated with obtaining that information.
- 3 I would not have a test that could cause miscarriage of pregnancy, even if the chance is very small.
- 4 I would end a pregnancy if affected by a genetic condition or congenital anomaly.
- 5 I want information about my pregnancy before sharing the news with my friends or family.

- 6 I have more anxiety worrying about the possibility that my baby may have special health needs, than if I knew for sure and could prepare.
- 7 I do not want a test that would tell me if I have a genetic condition.
- 8 I would rather know before birth if the baby has a genetic condition or congenital anomaly.
- 9 I want to get as much information about my pregnancy as I can before having diagnostic testing.
- 10 I value information that is more precise for a smaller number of conditions (such as Down syndrome) rather than less precise information about more conditions.
- 11 The cost of the testing options could influence my decision.



*“Improving the quality of obstetrical medical services by providing state of the art educational programs, and evidence-based, statistically valid monitoring systems to evaluate current practices and facilitate the transition of emerging technologies into clinical care”*

**Perinatal Quality**  
FOUNDATION

# PQF / California CDPH Partnership

- Partnership to Provide GEM Modules to CA Providers ([https://bit.ly/CA\\_GEM\\_Partner](https://bit.ly/CA_GEM_Partner))
- Practice Site Code: **CDPH1234**
- support@perinatalquality.org