The psychosocial component of genetic counseling is often one of the most difficult for students to master due to the perception that psychosocial constructs are less concrete. This class is designed to arm you with the knowledge and background needed to excel in psychosocially charged situations as well as to provide you with practical examples and role play scenarios. At the conclusion of the course, students should be able to:

- Learn how to elicit client expectations and set a mutually agreed upon agenda
- Appreciate how active listening and interviewing skills are used to build rapport and to identify and respond to client concerns
- Have a baseline working knowledge of psychosocial models as they apply to genetic counseling
- Describe a range of genetic counseling techniques such as tailoring, flexibility, and risk perception, that help facilitate informed decision making
- Recognizing the importance of the lived experience for individuals with genetic conditions

Course Instructors

Claire N Singletary, MS, CGC  Jennifer Czerwinski, MS, CGC  
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Office: UTPB 1217  Office: UTPB 1217
713-486-2294 (office)  713-486-2290 (office)

Attendance

Attendance is mandatory for all assigned classes. Missing more than one class for any reason (excused or unexcused) will result in a reduction in the student’s final letter grade by one full letter grade. Exceptions will only be made for an illness with a doctor’s note. Being tardy to two classes by more than 5 minutes is considered an unexcused absence.
<table>
<thead>
<tr>
<th>Date</th>
<th>Topic</th>
<th>Facilitator(s)</th>
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<tbody>
<tr>
<td>8/14/18</td>
<td>Getting started = know your client, contract, and build rapport</td>
<td>Claire Singletary</td>
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<tr>
<td></td>
<td>1. Uhlmann, Ch 3 (p71-76), Ch 5 (p135-137 and p155-166)</td>
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<td></td>
<td>2. McCarthy-Veach Ch 2</td>
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<td>3. Weil p 94-102</td>
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<tr>
<td>8/21/18</td>
<td>pyramid; Open-ended questions</td>
<td>Claire Singletary</td>
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<td></td>
<td>1. McCarthy Veach Ch 5, 6</td>
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<td>2. Ch 3 Uhlmann p76-90</td>
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<td>3. Microskills Pyramid and Intentional Questioning</td>
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<td>8/28/18</td>
<td>Listening and Reframing; Nonverbal Cues</td>
<td>Claire Singletary</td>
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<tr>
<td></td>
<td>1. McCarthy Veach, Ch 3</td>
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<td></td>
<td>2. Weil, Ch 3 p56-68</td>
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<tr>
<td>9/04/18</td>
<td>Primary Empathy</td>
<td>Claire Singletary</td>
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<td></td>
<td>1. McCarthy Veach 4</td>
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<tr>
<td>9/11/18</td>
<td>Flexibility and Tailoring I: Word Choice, Numeracy</td>
<td>Jen Czerwinski</td>
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<tr>
<td></td>
<td>1. Uhlmann, Ch 6 and Ch 7 to p 224</td>
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<td>4. Ch 4, Leroy, *Genetic Counseling Practice: Advanced Concepts and</td>
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<td>Skills*</td>
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<td>5. Ch 7 (p 173 – 189), McCarthy Veach *Facilitating the Genetic</td>
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<td>Counseling Process*</td>
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<td><strong>Complete VARK – bring completed questionnaire to class</strong></td>
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<tr>
<td>9/18/18</td>
<td>Flexibility and Tailoring II: Working with adolescents and</td>
<td>Jen Czerwinski</td>
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<td></td>
<td>individuals with intellectual disability</td>
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<tr>
<td></td>
<td>1. Weil, Ch 6 p 199-213 and Leroy, Ch 11 p272-275</td>
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<td>2. Leroy, Ch 12 (see also NSGC book by Finucane, available through</td>
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<td>the Program, if you would like more information)</td>
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<td>Review prior week’s readings</td>
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<td>Working with women with ID fact sheets due in class</td>
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<tr>
<td>Date</td>
<td>Topic</td>
<td>Assignments</td>
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</table>
| 9/25/18    | Flexibility and Tailoring III: Decision Making Role Plays & Assignment Presentations | 1. Uhlmann, Ch 7 224 - 243  
2. Ch 7 (p 190 – 201), McCarthy Veach *Facilitating the Genetic Counseling Process*  
Risk perception/tailoring assignment due in class  
Complete survey [https://uthtmc.az1.qualtrics.com/jfe/form/SV_ahFeDo86U5Y4sWF](https://uthtmc.az1.qualtrics.com/jfe/form/SV_ahFeDo86U5Y4sWF) | Jen Czerwinski        |
| 10/02/18   | Difficult Patients: Coping, Resistance, (Counter)Transference I        | 1. McCarthy Veach Ch 9  
2. McCarthy Veach Ch 12 (p 329-333)                                                      | Claire & Jen        |
| 10/9/18    | Difficult Patients: Coping, Resistance, (Counter)Transference II - Role Plays | 1. McCarthy Veach Ch 12 (p 333-351)  
2. Complete the countertransference checklist on pg 259 in MV/copy on the drive. | Claire & Jen        |
| 10/16/18   | Life Cycle; Person First Language; Lived Experience                    | 1. Weil, Chs 1 and 2 to p34.  
2. Welcome to Holland - [http://www.nas.com/downsyn/holland.html](http://www.nas.com/downsyn/holland.html) by Emily Perl Kingsley  
3. Holland Schmolland by Laura Kreuger Crawford  
4. Person First Language Sheet & FAQ by Kathie Snow | Claire Singletary    |
| 10/23/18   | Psychosocial Library                                                   | Discussion of the books read 5 min presentations for each book  
Written book summaries due | Jen & Claire          |
| 10/30/18   | Breaking Difficult/Bad News                                           | 1. Weil Ch 6 p161-8  
6. Resta, Bob – I didn’t want to tell you poem

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<thead>
<tr>
<th>Date</th>
<th>Event</th>
<th>Instructor(s)</th>
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<tr>
<td>11/06/18</td>
<td><strong>Psychosocial Quiz</strong>&lt;br&gt;Multiple choice questions with vignettes on psychosocial topics&lt;br&gt;Approximately 10 questions – 20 min max time</td>
<td>Claire &amp; Jen</td>
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<td>11/13/18</td>
<td><strong>NO CLASS – NSGC</strong></td>
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<tr>
<td>11/20/18</td>
<td><strong>NO CLASS - PNGC class in this time slot</strong></td>
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<td>11/30/18</td>
<td><strong>FINAL EXAM – Standardized Patient in the SCSC</strong></td>
<td>Jen &amp; Claire</td>
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<td>12/04/18</td>
<td><strong>Huntington Disease Immersion Exercise Presentations (1 hr)</strong></td>
<td>Jen Czerwinskij</td>
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<td>Huntington Assignment Discussion in class</td>
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<td></td>
<td><strong>Support Groups (1 hr)</strong></td>
<td>Rebecca Carter</td>
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<td>Support group rationale&lt;br&gt;Class presentations and discussion</td>
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<td></td>
<td>Assignments due - HD, Support group, SP write up</td>
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</table>

**Assignments:**

1. **Participation in role plays and discussion (5pts)**<br>Complete the readings as assigned for class each week and participate in weekly class discussions and role plays. Students must participate in role plays to receive full credit for participation.

2. **Working with women with intellectual disability fact sheet (10 pts)**
Read Chapter 12 by Finucane in the *Genetic Counseling Practice: Advanced Concepts and Skills*. Please make yourself a fact sheet with details on tips for counseling women with mental retardation. You may also choose to skim *Working with Women Who Have Mental Retardation: A Genetic Counselors Guide* by Brenda Finucane. You may borrow the book from the GCP. Topics to include in your fact sheet include IQ ranges, developmental characteristics of preoperational stage, what is needed for informed consent, inelegant goals, and strategies for genetic counseling. Turn in a copy of your fact sheet in class.

3. **Psychosocial library reading assignment and summary (10 pts)**
   **no more than two students should read the same book – sign up in class**

   Choose 2 books from first four sections: emotional, prenatal, pediatric, and adult/cancer. You may not choose both of your books from the same section. Summarize the relevant points from each book that you read in either bullet point or paragraph format. The summary should be no shorter than one page and no longer than two pages. Students who turn in the completed assignment on time and participate in the class discussion with knowledgeable points about their works will receive full credit. You are encouraged to read additional selections from the Fun Fiction section on your own in the future. The summaries are due on the day we discuss books in class.

4. **Support group assignment (10 points - half for in person, half for online)**
   **warning – start early in semester so that you can get this done! (due Dec 4)**
   **no more than one student to a support group or specific disorder for chat group**
   
   a. Attend one meeting of an in person support group in the greater Houston area. Consult the attached list of local support group information or research on your own. Please call the contact number/individual to verify the meeting location, time, and topic and to ask permission to attend the meeting. No more than two students should attend a specific support group. At the meeting, you should observe the group dynamics. Speak with the group contact person and ask for their comments on the organization of the support group (i.e. how they made it work, what didn’t work, how formal/informal, etc.).

   b. Join an online chat group/yahoo group/discussion board for a genetic condition. Seek appropriate permission to join the group. Follow the discussion thread for at least one month. Observe how the group responses to posts. Is inaccurate information taken down? Corrected? Is medical advice given? Does a health care provider monitor the group?

   c. You are required to turn in a one page bulleted summary of your experience and to present an oral summary of your experience in class. Compare and contrast the in person and online environments. What types of coping mechanisms, stages of grief, etc, did you observe? What type of group might you personally prefer? How will this experience change how you refer patients to support groups?

5. **Field Trips to Local School and Residential Facility (5 points each)**

   A. The Rise School [http://www.riseschool.org](http://www.riseschool.org)
   On October 16 from 9am to 11:30 am – tour the Rise school and spend the morning in an integrated preschool classroom. PT, OT, Speech and other therapy is on site. Located across 288 from the TMC at 5618 H. Mark Crosswell Jr St, Houston, TX 77021

   B. The Center – [http://thecenterhouston.org/services/residential-services](http://thecenterhouston.org/services/residential-services)
Tentative: TBD from 10am to noon - tour the facility, including residence buildings and workshops. Carpooling is encouraged. Located in the River Oaks area at 3550 W. Dallas, Houston, TX 77019

6. **Psychosocial Quiz – (10 pts)**

You will be given a quiz over the psychosocial concepts discussed over the course of the semester. Questions will be presented in a vignette style with multiple choice answers where you are asked to select the ‘next best step’. The quiz will likely consist of 10 questions.

7. **Tailoring & Risk Perception - Group Assignment**

a. Complete the VARK: bring completed questionnaire to class
   

b. Studies show that adults tend to prefer to learn in one of three main domains: auditory, visual, and kinesthetic/tactile. Since adults prefer to learn in different formats, it follows that patients will prefer to learn risk information in different ways. Therefore, genetic counselors need different tools at their disposal to explain risk.

<table>
<thead>
<tr>
<th>Auditory - listening and discussing</th>
<th>Visual - seeing</th>
<th>Kinesthetic - learn by doing/touching/tactile</th>
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<tbody>
<tr>
<td>Q&amp;A, songs, acronyms, metaphors, definitions</td>
<td>Diagrams, charts, color, flowchart, maps, photos</td>
<td>puzzle, building things, toys, props, role play</td>
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<tr>
<td>Identify sounds related to an experience</td>
<td>Have a sharp, clear picture of an experience</td>
<td>Develop a strong feeling towards and experience</td>
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<tr>
<td>I hear you clearly; I want you to listen... This <strong>sounds</strong> good</td>
<td>Do you <strong>make pictures</strong> in your head Do you have <strong>visual images</strong> in your head as you are talking and listening to me? Can you <strong>see</strong> what I am saying?</td>
<td>Do you <strong>feel</strong> what you are saying? Are you in <strong>touch</strong> with what I am saying?</td>
</tr>
<tr>
<td>How do you hear this situation going? What do you hear that is stopping you? <strong>Sounds</strong> heavy.</td>
<td>How do you <strong>see</strong> the situation? What do you <strong>see</strong> stopping you? This <strong>looks</strong> good. Do you <strong>see</strong> what I am <strong>showing</strong> you?</td>
<td>How do you <strong>feel</strong> about this situation? I'm <strong>getting a handle</strong> on this material. Let's <strong>move</strong> together. Does what I am putting you in <strong>touch</strong> with feel right? <strong>Sounds</strong> heavy.</td>
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</table>

Since we most often start with a verbal/auditory explanation, you and your genetic counseling colleagues (other members of your assigned group) have been asked by your supervisor to create a visual and a kinesthetic way to creatively convey risk information for your patient.

Each group will present in front of the class.

1 – Cancer – Lifetime risk of 27-55% for ovarian cancer with a BRCA1 or 2 mutation
   
   Team A - Kaitlyn and Aranza
   
   Team B - Wendi and Emily

2 – Medical Genetics – Chance for Fragile X carrier (of 75 repeats) to have a child with Fragile X syndrome
   
   Team C - Luke, Addison, Autumn
8. **Huntington disease role immersion exercise**

   Watch one of two assigned documentaries on HD:
   1. The Lion’s Mouth Opens – Brad, Sarah, Addison, Emily, Aranza  
      https://gostream.movie/film/1337-the-lions-mouth-opens.html# GoMovies
   2. Twitch – Autumn, Caroline, Luke, Wendi, Kaitlyn  
      (available on DVD to check out from Claire’s office)

   Keep a daily diary and write a summary reflection: Assume the persona of an individual who is at risk for Huntington Disease. Assign a parent to have HD and a backstory. Consider the impact within your personal situation (married, dating, single, siblings, etc.). This assignment will span the weeks of Nov 1 to Nov 14. During the first week you will plan your genetic counseling appointment, have HD DNA testing performed on Nov 2, receive your results on Nov 6, and journal about the impact of the results until Nov 13. On the final day (Nov 14), consider and summarize, in writing, how this exercise has impacted how you will practice as a genetic counselor and/or how you view your patients. Please do not discuss your feelings or experience with each other until we have the interactive presentations. Submit your finished diary and summary on December 4. We will discuss your thoughts and feelings about the exercise in class on December 4.

9. **Final Exam – Standardized Patient Scenario in the SCSC**

   The final exam will take place on November 30th in the Surgical and Clinical Skills Center. Approximately two weeks prior to the encounter you will receive additional information regarding the case so that you may prepare the informational aspects. You will be graded on your ability to employ the basic psychosocial skills that are discussed in this course as well as to provide baseline patient education. Your session will be viewed by the course instructor and an additional genetic counselor.

**Grading**

Students will be graded on level of participation, attendance, and completion/quality of course assignments.

- Psychosocial library annotated bibliography          10 pts
- Working with women with intellectual disability fact sheet      10 pts
- Tailoring/Risk perception group assignment                   15 pts
- Support group assignment                                      10 pts
- Huntington disease immersion exercise/paper                   15 pts
- Field trip participation                                       10 pts
- Psychosocial Quiz                                              10 pts
- Class Participation                                            5 pts
- Final exam – standardized patient scenario                    15 pts
- Total                                                        100 pts

100-90% = A   89-80% = B   79-70% = C   69-60% = D   <60 = F
Texts:
- Weil (2000) *Psychosocial Genetic Counseling*
- Veach, LeRoy, and Bartles (2018) *Facilitating the Genetic Counseling Process*

Other psychosocial references:


**Psychosocial Aspects 2018 – Reading List**

General emotional/psychosocial

1. When Bad Things Happen to Good People (Harold Kushner)
2. Tuesdays with Maurie (Mitch Albom)
3. On Death and Dying (Elisabeth Kubler-Ross)
4. I Know Just How You Feel? Avoiding the Clichés of Grief (Erin Linn)
5. The Light Within: The Extraordinary Friendship of a Doctor and Patient Brought Together by Cancer (Lois M. Ramondetta & Deborah Sills)
6. The Last Lecture (Randy Paush)

Prenatal

1. Choosing Naia (Mitchell Zuckoff) - prenatal diagnosis of Down syndrome
2. Expecting Adam: A True Story of Birth, Rebirth, and Everyday Magic (Martha Beck) – prenatal diagnosis of Down syndrome
3. Searching for the Stork: One Couple’s Struggle to Start a Family (Marion Lee Wasserman)

Pediatric
1. Grief Dancers (Susan Zimmerman) – daughter with Rett syndrome
2. Before and After Zachariah: A True Story about a Family and a Different Kind of Courage (Fern Kupfer)
3. Intensive Care: a family love story (Mary-Lou Weisman) – child with DMD
4. Riding The Bus With My Sister: A True Life Journey (Rachel Simon)
5. Another Season: A father’s story (Gene Stallings) – son with Down syndrome
6. Babyface: A Story of Heart & Bone. (Jeanne McDermott) - describes the turbulent time following the birth of a child with Apert syndrome
7. The Child Who Never Grew (Pearl Buck) – daughter with undiagnosed PKU
8. When Snow Turns to Rain (Craig Schulze) - father of boy with autism
9. As Nature Made Him: the boy who was raised as a girl (John Colapinto)
10. The Power of Two: a twin triumph over cystic fibrosis (Isabel Stenzel Byrnes and Anabel Stenzel)
11. The Cure: How a Father Raised $100 Million and Bucked the Medical Establishment in a Quest to Save His Children (Geeta Anand)
12. Schuyler’s Monster: A Father’s Journey with his Wordless Daughter (Robert Rummel-Hudson)

**Adult/Cancer**

1. It's Always Something (Gilda Radner) or Gilda's Disease: Sharing Personal Experiences and a Medical Perspective on Ovarian Cancer (Steven Piver)
2. Why I wore lipstick to my mastectomy (Geralyn Lucas) – an honest, perceptive memoir from a feisty survivor who’s willing to discuss every detail
3. Mapping Fate: A memoir of family, risk, and genetic research (Alice Wexler) – Huntington’s disease
4. Bald in the Land of Big Hair (Joni Rodgers) – an inspirational book for cancer patients
5. Second Act (Barbara Barrie) – author’s struggle with colon cancer
6. An Unquiet Mind (Kay Redfield) - the author has bipolar disorder
7. Breakthrough: The race to find the breast cancer gene (Kevin Davis and Michael White)
8. Before I say goodbye: Recollections and observations from one woman's final year (Ruth Picardie) – journalist's emails and columns describing her diagnosis and treatment of breast cancer
9. Cancer Vixen: A True Story (Marisa Marchetto)
10. Apron Strings: Inheriting courage, wisdom, and...breast cancer (Diane Tropea Greene)
11. Pretty Is What Changes (Jessica Queller) – written by a woman who was at risk for hereditary breast and her choices to defied her destiny
12. Still Alice (Lisa Genova)
13. Sick Girl (Amy Silverstein) – women who suddenly falls ill in her twenties
14. Previvors (Dina Roth Port) – Facing the Breast Cancer Gene and Making Life-Changing Decisions
15. When breath becomes air

**Other Genetics Books available in the suite for check out:**

1. My Sister’s Keeper (Jodi Picoult) - the difficult choices a family must make when a child is diagnosed with a terminal illness
2. Seize the Night or Fear Nothing (Dean Koontz) – xeroderma pigmentosum
3. Jewel (Bret Lott) – child with Down syndrome
4. Flowers for Algernon (Daniel Keyes) – science fiction: a man with mental retardation has surgery to make him smart
5. The Memory Keepers Daughter (Kim Edwards) – physician’s nurse takes twin daughter with Down syndrome to raise on her own
6. The Curious Incident of the Dog in the Night-time (Mark Haddon) - novel about love and bravery through the eyes of a British autistic boy
7. Middlesex (Jeffrey Eugenides) - describes the childhood of a man affected with 5-alpha reductase deficiency, i.e. how he was born as a girl and learned as a teenager that he was a boy
8. As I Lay Dying (William Faulkner)
9. Family Tree (Barbara Delinsky) – Caucasian family has African American child
10. Handle with Care (Jodi Picoult) – A daughter with osteogenesis imperfecta
11. Stones from the River (Ursula Hegi) - a dwarf living in Germany during the two World Wars
12. Mendel's Dwarf (Simon Mawer)
13. Almost Chimpanzee (Jon Cohen) – Redrawing The Lines That Separate Us From Them
14. The Condition (Jennifer Haigh)
15. Intensive Care (Mary-Lou Weisman) – A Family Love Story
16. The Tenth Chronicle (Jodi Picoult)
17. What Remains (Carole Radziwill) – A Memoir of Fate, Friendship & Love
18. The Bereaved Parent (Harriet Sarnoff Schiff)
20. Partial View (Cary Smith Henderson) – An Alzheimer’s Journal
21. The Story of the Beautiful Girl (Rachel Simon)
22. There Are No Children Here (Alex Kotlowitz) – The Story of Two Boys Growing Up in the Other America
23. On Children and Death (Elisabeth Kubler-Ross)
24. The Immortal Life of Henrietta Lacks (Rebecca Skloot)
25. Gifts (Kathryn Lynard Soper) – Mother’s Reflect on How Children with Down Syndrome Enrich Their Lives
26. The Girls (Lori Lansens)
27. Positive Results (Loi Morris & Ora Gordon, MD) – Making the Best Decisions When You’re at High Risk for Breast or Ovarian Cancer
28. Light at the End of the Tunnel (Linda Chann Rapp)

**Houston Area Support Groups**

[http://www.memorialhermann.org/cancer/support-groups/](http://www.memorialhermann.org/cancer/support-groups/)
For support groups not listed or for questions, call 713.222.CARE (2273).

Hydrocephalus support group - Jamie Wright at: houstonsupport@hydroassoc.biz They meet the 4th Thursday of every month at 6:00pm in the 3HP conference room on the 3rd floor of Hermann Pavilion.

MDAnderson Support groups:

Family Services of Greater Houston – 713-861-4849

Planned Parenthood – 713-522-6363

Down Syndrome Association of Houston – P.O. Box 303 Houston, 77024 713-682-7237, www.dsah.net

Texas NF Foundation – http://texasnf.org/Meet_Others_with_NF/Support

MEND (Mommies enduring Neonatal Death) – Christian organization for miscarriage, stillbirth, and early infant death, www.mend.org. Support group meets 3rd Thursday of each month. Contact: Jaimie Crump, jaimie@mend.org, 281-374-8528

Please feel free to search out area support groups on your own and send to Claire for approval