One of the most complicated aspects of life is bringing a new healthy life into the world. Beyond the actual birthing process, there are many considerations that need to be explored before the day of delivery. Prenatal counseling is a very important aspect of the birthing process that is often overlooked.

Expectations: Women's Health and Birthing Center, stresses the importance of individual care. I will be volunteering there during the spring semester working with couples and counseling them about concerns that arise before delivery. Through this experience, I will compile a guide for prenatal counseling of both parents. This guide will include information about considerations that the parents-to-be should be aware of such as PKU, Alpha Fetoprotein screening, HIV, Rh incompatibility, Group B Streptococcus, ethnicity complications, Fetal Alcohol Syndrome, Cystic Fibrosis screening and other prenatal concerns. The guide will also include the consent forms for the HIV test and AFP test that are mandated by the state of Indiana along with tips for the counselor on each subject.

The experience of counseling parents-to-be will prepare me with experience necessary for my future career as a genetic counselor. One day I hope to work as a prenatal/perinatal genetic counselor. I believe that this thesis project will not only benefit me in preparation for my career, but will also benefit future prenatal counselors.
Guide For Prenatal and Pediatric Counseling
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      1- Fetal Alcohol Syndrome Information Sheet
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V. Genetic Counseling Information
Guide Explanation

This section of the guide will explain the general purpose of the guide and how it is structured.

The sole purpose of this guide is to help the medical professional involved in prenatal and pediatric health explain some of the most common procedures and information available for the expectant mother. This guide gives Information Sheets on a variety of topics. The Information Sheets are meant to be handed out to the patients during appropriate times in pregnancy. Most of these are focused on problematic issues that surround pregnancy and risk factors for birth defects. Also included in this manual is a Quick Sheet for most of the Information Sheets. This is to be used as a quick guide for the medical professional. It is intended to highlight the most important points of the Information Sheet and may help with questions that a patient may have. Both the Information Sheets and Quick Sheets can be found following the forms in the beginning of the guide.

The beginning of the guide has some of the common general information forms for both the patient and the medical professional to fill out. These were made with specific intentions and should be used in a medical setting in which they are appropriate. The guide is set up so that the general patient information forms are at the beginning followed by the forms intended for the use of the medical professional.

This guide is intended to be used by medical professionals and has undergone revision by a Certified Nurse Midwife along with other members of the medical community. This is not a supplement for any type of patient care, including genetic counseling when appropriate, and can be used in conjunction with counseling when necessary.
General Patient Information Forms
Guide For Prenatal and Pediatric Counseling

An Honors Thesis (Honors 499)

by

Adam Hott

Thesis Advisor

Dr. William Rogers

(Signature)

Ball State University

Muncie, Indiana

May 5, 1999

Expected Graduation Date:

May 8, 1999
PATIENT REGISTRATION

Patient Name
________________________ (Last) (First) (M.I.)

Address __________________________ City __________ State ___ Zip __________

Home Telephone __________________________ Work Phone __________________________

Employer __________________________ Address __________________________

Date of Birth __ / __ / __ Social Security Number ___ -- ___

Ethnic Background __________________________

Marital Status: Married Single Divorced Widowed Partners

Responsible Party
________________________ (Last) (First) (M.I.)

Address __________________________ City __________ State ___ Zip __________

Home Telephone __________________________ Work Phone __________________________

Employer __________________________ Address __________________________

Date of Birth __ / __ / __ Social Security Number ___ -- ___

Insurance Company Name __________________________

Policy Number __________________________ Other ID Number (Group Number) __________________________

Member's Name __________________________ Relationship to Patient __________________________

Address (if different than patient or responsible party):
Street __________________________ City __________ State ___ Zip __________

Home Telephone __________________________ Work Phone __________________________

Employer __________________________ Address __________________________

Referred By: __________________________

How did you hear about us? __________________________

Patient's Signature __________________________ Date __________

*If you have any questions about insurance coverage, payment of services, or anything else be sure to ask.
CONSENT FOR TREATMENT

I hereby request that a certified nurse midwife or physician to evaluate me and provide appropriate treatment when indicated.

The nature and purpose of the procedures and treatment have been and will be explained to me. I understand that a midwife or physician will be available to answer any questions I may have.

I realize that I have the right to refuse any treatment and seek second opinions without repercussions on the care I receive.

Referrals will be made for further diagnosis and/or treatment where indicated. I understand that if follow up is needed, I will assume responsibility for such follow up.

If immunizations are provided, I release Expectations Women’s Health and Childbearing Center, its medical staff and its employees from any liability arising out of or connected with immunizations.

I understand that, in general, the care received at Expectations Women’s Health and Childbearing Center is confidential. I understand that the exceptions required by Indiana state law are: positive results of tests for certain sexually transmitted diseases and sexual abuse, which must be reported to the Child Protective Services Agency when the victim is under the age of 18.

If a laboratory test(s) is done, I release Expectations Women’s Health and Childbearing Center and others authorized by them to use information contained in my medical record for statistical purposes, with the understanding that confidentiality will be maintained.

Signed: ____________________________ Date: ________________
(Patient or parent if minor)

Printed: ____________________________ Date: ________________
(Patient or parent if minor)

I witness the fact that the patient received, read and states that she understood the information above.

Witness: ____________________________ Date: ________________
AUTHORIZATION TO RELEASE MEDICAL RECORDS

I hereby authorize __________________________ to release information included in my record to

____________________________________
(Provider name)

____________________________________
(Provider Address)

This authorization includes medical and demographic information as may be contained in my medical record including diagnosis and treatment information. I understand that this may include all or part of my medical record.

This authorization will remain in force until the requesting provider has been supplied with the desired information. Additional requests thereafter will require a separate authorization.

Signed: ________________________________ Date: ________________
(Patient or parent if minor)

Witness: ________________________________ Date: ________________
REVISIT

Patient Name

(Last) (First) (M.I.)

Address _______________ City __________ State __ Zip ______

Today's Date ___ / ___ / ___ Birth date ___ / ___ / ___ Age ___

Emergency Contact

Name _______________________________________________________

(Last) (First) (M.I.)

Address _______________ City __________ State __ Zip ______

Home Telephone __________________ Work Phone ________________

Marital Status: Married Single Divorced Widowed Partners

____ No ____ Yes Are you going to school? School Name ______________________

__________________________________________________________

Personal and Family History Update

What method of birth control are you now using?

__________________________________________________________

Are you having problems with this method? ____ No ____ Yes

If yes, please explain __________________________________________________________________________

Do you wish to change your method? ____ No ____ Yes

If yes, please state what type __________________________________________________________________

Have you had any serious illness/surgery/pregnancy since your last exam here? ____ No ____ Yes

If yes, please explain __________________________________________________________________________

Do you smoke? ____ No ____ Yes About how many packs per day? __________________________

Are you taking any medications or drugs? ____ No ____ Yes

If yes, what are you taking? ___________________________________________________________________

Are you having any problems you wish to discuss today? ____ No ____ Yes

If yes, please explain _________________________________________________________________________

Female
On what date did you start your last period? _____/_____/_____  Was it normal?  __No __Yes
Do you have any allergies? (drugs, metals, etc.)  __No __Yes
   If yes, what type of allergies do you have?
________________________________________________________
________________________________________________________
Do you use STI/AIDS protection?  __No __Yes
   If yes, what type do you use?  condoms  spermicide  abstinence  other _______
On what date did you start your last period? _____/_____/_____  Was it normal?  __No __Yes
Do you have any allergies? (drugs, metals, etc.)  __No __Yes
   If yes, what type of allergies do you have?
________________________________________________________
________________________________________________________
Do you use STI/AIDS protection?  __No __Yes
   If yes, what type do you use?  condoms  spermicide  abstinence  other _______
Does anyone in your immediate family have a history of (please check all that apply)
( ) diabetes  ( ) heart attack  ( ) breast cancer  ( ) high cholesterol  ( ) stroke
( ) uterine cancer  ( ) high blood pressure  ( ) blood clots  ( ) colon cancer
Since your last exam have you had:
STD (syphilis, gonorrhea, herpes, chlamydia)?  __No __Yes
   Sever depression?  __No __Yes
   Serious infection?  __No __Yes
   Abdominal pain?  __No __Yes
   Chest pain or shortness of breath?  __No __Yes
   Infection of the tubes, uterus, or ovaries?  __No __Yes
   Migraines, bad headaches, dizziness?  __No __Yes
   Leg pain, tenderness, swelling?  __No __Yes
   High blood pressure?  __No __Yes
   Unusual vaginal bleeding (between periods)?  __No __Yes
   Breast lump or vaginal discharge?  __No __Yes
   Blurring or change in vision?  __No __Yes
   Jaundice or yellow color skin?  __No __Yes
   Current problem with physical abuse?  __No __Yes
   New sex partner?  Male  Female  Both

Patient Name (please print) ____________________________ (Last)  (First)  (M.I)
Patient Signature ____________________________
Staff Signature ____________________________

Female
Patient Name

(Last) (First) (M.I.)

Address ____________________________ City __________ State __ ______ Zip ______

Today's Date __ / __ / __ Birth date __ / __ / __ Age ______

Emergency Contact

Name ____________________________ (Last) (First) (M.I.)

Address ____________________________ City __________ State __ ______ Zip ______

Home Telephone ____________________________ Work Phone ____________________________

Marital Status:  Married   Single   Divorced   Widowed   Partners

__ No  __ Yes  Are you going to school?  School Name ____________________________

Personal and Family History Update

What method of birth control are you now using?

__________________________________________________________

Are you having problems with this method?  __ No  __ Yes
If yes, please explain
g
__________________________________________________________

Do you wish to change your method?  __ No  __ Yes
If yes, please state what type ____________________________

Have you had any serious illness/surgery/pregnancy since your last exam here?  __ No  __ Yes
If yes, please explain ____________________________

Do you smoke?  __ No  __ Yes  About how many packs per day?  ________________

Are you taking any medications or drugs?  __ No  __ Yes
If yes, what are you taking?  ______________________________________

Are you having any problems you wish to discuss today?  __ No  __ Yes
If yes, please explain ______________________________________

Male
REVISIT CONTINUED

On what date did you start your last period? ______/_____/______  Was it normal?  ____No  ____Yes
Do you have any allergies? (drugs, metals, etc.)  ____No  ____Yes
   If yes, what type of allergies do you have?

Do you use STI/AIDS protection?  ____No  ____Yes
   If yes, what type do you use?  condoms  spermicide  abstinence  other ______

Does anyone in your immediate family have a history of: (please check all that apply)
( ) diabetes  ( ) heart attack  ( ) testicular cancer  ( ) high cholesterol  ( ) stroke
( ) prostate cancer  ( ) high blood pressure  ( ) blood clots  ( ) colon cancer

Since your last exam have you had:
   STD (syphilis, gonorrhea, herpes, chlamydia)?  ____No  ____Yes
   Sever depression?  ____No  ____Yes
   Serious infection?  ____No  ____Yes
   Abdominal pain?  ____No  ____Yes
   Chest pain or shortness of breath?  ____No  ____Yes
   Migraines, bad headaches, dizziness?  ____No  ____Yes
   Leg pain, tenderness, swelling?  ____No  ____Yes
   High blood pressure?  ____No  ____Yes
   Blurring or change in vision?  ____No  ____Yes
   Jaundice or yellow color skin?  ____No  ____Yes
   Current problem with physical abuse?  ____No  ____Yes
   New sex partner?  Male  Female  Both  ____No  ____Yes

--------------------------------------------

Patient Name (please print) ___________________________ 
   (Last) (First) (M.I)

Patient Signature ___________________________ 

Staff Signature ___________________________ 

--------------------------------------------

Male
Consent Form

As parent/guardian of __________________, I have instructed my physician and/or advanced practice nurse and Expectations to administer the ____________ Vaccine to my child. I have been provided written information about the vaccine. I have had a chance to ask questions which were answered to my satisfaction. I believe I understand the benefits and risks of this vaccine.

Witness __________________ Parent/Guardian ___________________ Date __/__/____

Vaccine Administration Record

Date __/__/____ Manufacturer __________ Lot # __________ Site given _________

Observation of Post Vaccine Reaction No_____ Yes _____ If yes, explain _________

Vaccine administered by __________________

Declination Form

As parent/guardian of __________________, I have instructed my physician and/or advanced practice nurse at Expectations NOT to administer ____________ vaccine to my child. I have been provided written information about this vaccine. I have had a chance to ask questions which were answered to my satisfaction. I believe I understand the benefits and risks of this vaccine.

Witness __________________ Parent/Guardian ___________________ Date __/__/____
Medical Information
Sheets for Medical Professionals
## Medical History

### Patient Information

- **Last**: [Name]
- **First**: [Name]
- **M.I.**: [Name]
- **Address**: ____________
- **City**: ____________
- **State**: ____________
- **Zip**: ____________
- **Today's Date**: __/__/__
- **Birth Date**: __/__/__
- **Age**: __
- **Reason for Today's Visit**: _______________________

### Family History

<table>
<thead>
<tr>
<th>Blood relatives (parents, sisters/brothers, grandparents) history</th>
<th>Personal Medical History</th>
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<tbody>
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<td>Yes</td>
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<td>No</td>
<td>Yes</td>
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<tr>
<td>No</td>
<td>Yes</td>
</tr>
</tbody>
</table>

### Last check up: __/__/__

### Allergies:

- [Name]
- [Name]
- [Name]

### Medications: (Please include all vitamins and herbs)

- [Name]
- [Name]
- [Name]

### Hospitalizations/Operations

<table>
<thead>
<tr>
<th>Type</th>
<th>Year</th>
<th>M.D.</th>
<th>Hospital</th>
</tr>
</thead>
<tbody>
<tr>
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</tr>
</tbody>
</table>
WOMEN'S HEALTH HISTORY

Patient Name

(Last) (First) (M.I.)

Address ____________________________ City ____________________________ State __ Zip ____________

Today's Date ___ / ___ / ___
Birth date ___ / ___ / ___
Age ___

Reason for Today’s Visit? ________________________________________________________________


Pregnancy History

<table>
<thead>
<tr>
<th>Live Births</th>
<th>Miscarriages</th>
<th>Still Births</th>
<th>C. Sections</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abortion(s)</td>
<td>Fetal Deaths</td>
<td>Genetic Abnormalities</td>
<td>Pre Eclampsia</td>
</tr>
<tr>
<td>Total Pregnancies</td>
<td>Number of Living Children</td>
<td>Ages</td>
<td></td>
</tr>
</tbody>
</table>

Birth Control History

Last birth control used:  □ Foam  □ Condom  □ Pills  □ Other

Problems with Birth Control: ____________________________________________________________


Menstrual History

Patients using hormonal birth control, answer about periods before use of the hormonal birth control.

I had my first period at _____ years of age.

My periods usually occur about every _____ days and last about _____ days.

My flow is usually:  Light  Moderate  Heavy

<table>
<thead>
<tr>
<th>No</th>
<th>Yes</th>
<th>I have bleeding/spotting between periods</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>I have severe cramps/painful periods</td>
</tr>
<tr>
<td></td>
<td></td>
<td>I consider my periods normal</td>
</tr>
</tbody>
</table>

The first day of my last normal menstrual period was ___ / ___ / ___
Allergies (include metals, foods, and medications)

No ___ Yes ___ I have allergies/had allergic reactions to: ____________________________

Current Medications: (include vitamins and herbs)

______________________________

______________________________

______________________________

______________________________

No ___ Yes ___ Do you have a latex allergy?

______________________________

Current Information

No ___ Yes ___ Have you had a pap test? When was your last exam? __/__/____

No ___ Yes ___ Have you had an abnormal pap test? Please explain:

No ___ Yes ___ Is there a chance you have been exposed to an STD?

No ___ Yes ___ Have you had any abnormal pain?

No ___ Yes ___ Are you sexually active?

At what age was your first sexual intercourse experience?

On average how many times per month do you engage in sexual intercourse?

How many sexual partners have you had in your life?

No ___ Yes ___ Have you had a new sex partner in the past 60 days? (please circle one) Male  Female  Both

No ___ Yes ___ Do you think you might be pregnant?

No ___ Yes ___ Do you have bleeding, spotting, and/or pain after sex?

No ___ Yes ___ Do you have problems with your period? Please explain:

No ___ Yes ___ Do you smoke cigarettes?

On average, how many cigarettes do you smoke per day?

No ___ Yes ___ Are you more than 50% over your recommended weight.

No ___ Yes ___ Have you been forced to have sexual intercourse when you did not want to.

No ___ Yes ___ Are you a survivor of sexual abuse, physical abuse, and/or emotional abuse?

No ___ Yes ___ Are you HIV positive or do you have AIDS.
PEDIATRIC HEALTH AND PHYSICAL

Patient Name

(Last) (First) (M.I.)

Today's Date / / Birth date / / Age

PRESENT ILLNESS

Reason for today's visit:

Duration of illness: / / (Months) (Weeks) (Days)

Description of illness:


PAST MEDICAL HISTORY

Neonatal:

Normal Pregnancy? No Yes Description:

Duration Birth Weight lbs. oz.

Complications No Yes Description:

Feeding:

Good Suction? No Yes Complications:

Type of feeding?

Breast Bottle

Duration / / (Days) (Months) (Years)

Development:

Head up (2-3 mo.) No Yes Walks (12-16 mo.) No Yes
Smiles back (3-4 mo.) No Yes Fear of strangers (7-14 mo.) No Yes
Babbles (4 mo.) No Yes 1st Words (13 mo.) No Yes
Finger feeds (6-10 mo.) No Yes 1st Sentences (3 yrs.) No Yes
Sits (6-7 mo.) No Yes Tricycle (4 yrs.) No Yes

Pre-school screen:
Name ___________________ DOB ______ / ______ / ______

School: ____________________________
Age started ______ years old
Grades ____________________________________________
Comparison with Siblings: ____________________________________________

Unusual Diseases:
__________________________________________________________
__________________________________________________________
__________________________________________________________

Hospitalizations:
(Age) ______ (Reason) ______ (Hospital)
__________________________________________________________
__________________________________________________________
__________________________________________________________

(Vaccines: ____________________________ Meds: ____________________________
Allergies: ____________________________ Injuries: ____________________________
__________________________________________________________
__________________________________________________________
__________________________________________________________

FAMILY HISTORY  (Diseases that run in the family)

Mother: ____________________________________________
Father: ____________________________________________
Siblings: ____________________________________________

PHYSICAL EXAM

Height ______% ______ Weight ______% ______ Head Circ. ______% ______ Chest Circ. ______% ______
T ______ P ______ R ______ BP ______

General:
Skin jaundice rash
BMJ deform hip click
Ears TM low set
Eyes strabismus
Tongue cyanosis
Neck supple webbing
Chest
Heart murmurs
Femoral pulses

Abdomen masses spleen hernia
Genitalia descended testes hydrocele
Lymph nodes
Neuro cranial n.
sens-motor
cerebellar
DTRs
hopping

IMPRESSSION:
**Birth Factor Evaluation**

<table>
<thead>
<tr>
<th>Date</th>
<th>Heart Attacks/Strokes/Heart Disease</th>
<th>No</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>Diabetes/Gestational (During Pregnancy)</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>Mononucleosis/Hepatitis</td>
<td>Yes</td>
<td></td>
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<tr>
<td>No</td>
<td>Hyperlipidemia (High Cholesterol)</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>Epilepsy/Seizure Disorder</td>
<td>No</td>
<td></td>
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<tr>
<td>No</td>
<td>Migraine/Severe Headaches</td>
<td>No</td>
<td></td>
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<tr>
<td>No</td>
<td>Eye Problems/Visual Changes/Blurred Vision</td>
<td>No</td>
<td></td>
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<tr>
<td>No</td>
<td>Your childhood immunizations</td>
<td>No</td>
<td></td>
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<tr>
<td>No</td>
<td>Rheumatic Fever</td>
<td>No</td>
<td></td>
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<tr>
<td>No</td>
<td>Sickle Cell or other Anemia</td>
<td>No</td>
<td></td>
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<tr>
<td>No</td>
<td>Stomach/Bowel/Gastrointestinal Problems</td>
<td>No</td>
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<tr>
<td>No</td>
<td>Bladder/Kidney Disease</td>
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<td>No</td>
<td>Vaginal/Female organ infection/Discharge</td>
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<td>No</td>
<td>Uterine Abnormalities/Pain/Contractions</td>
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<td>No</td>
<td>Genetic Condition</td>
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<td>No</td>
<td>Breast Disease or Breast Surgery</td>
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<td>No</td>
<td>Abdominal Surgery</td>
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<tr>
<th>Date</th>
<th>Heart Attacks/Strokes/Heart Disease</th>
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Information Sheets
and Quick Sheets
Alpha Fetoprotein Test
Alpha-fetoprotein Test

The Alpha-fetoprotein test is used as an initial test fetal complications. It is a simple blood test done between 15-20 weeks in which the serum of the blood is extracted and then tested for a specific protein, alpha-fetoprotein. There is a range of normal levels that occur during pregnancy. A detection of increased levels has been shown to detect spina bifida or anencephaly in 80-85% of positive tests. A detection of decreased levels has been shown to detect a higher risk for Down’s syndrome and other chromosomal abnormalities such as Trisomy 18 when combined with other test results (HCG and E3).

The AFP test is not a definitive test. Because of the procedure used and the way in which the test is set up, there is up to a 90% or higher false positive rate is observed. The test is simply a screening test for RISK, not for diagnosis.

Additional tests are needed with abnormal AFP test results. Amniocentesis can check the actual amount of AFP in the amniotic fluid. Amniocentesis is a much more definitive test that requires extraction of amniotic fluid from the womb. Amniocentesis is 99% accurate in detection of spina bifida and can also be used for a more definitive diagnosis for Down’s syndrome. A CVS test may also be needed for diagnosis of Down’s syndrome.

Amniocentesis is required for the following reasons as a follow-up for AFP screening:

1- Screen positive for abnormal AFP levels suggesting Down syndrome, spina bifida, or Trisomy 18.
2- Family history of spina bifida
3- The mother is taking valproic acid (Depakote) or carbamazepine (Tegretol) for seizure disorder.
AFP Quick Sheet

- AFP testing is done through a test called TRIPLE SCREEN.
- Triple screen uses three protein markers to test for SPINA BIFIDA and DOWN SYNDROME.
- Triple screen is 80-85% accurate for detection of spina bifida and anencephaly.
- Triple screen has also been shown to detect higher risk for Down Syndrome and Trisomy 18.
- Triple screen has a 90% FALSE POSITIVE rate.
- ABNORMAL TEST RESULTS REQUIRE FURTHER TESTING FOR A DEFINITIVE ANSWER.
- Additional testing usually includes amniocentesis and ultrasounds.
AFP Screening Consent Form

The information provided to you explains the general procedure and background information you need for making a decision about having the test done. The American College of Obstetricians and Gynecologists recommends that this test be offered to patients who are concerned with the possibility of neural tube defects and Down syndrome. The cost of the test may be covered by your insurance and we will be glad to help you file for this. Some policies may not cover this test.

I have reviewed the information sheet on the AFP test and understand the risk of the procedure and the defects that it screens for. I also understand that this is a preliminary procedure that may need further testing for more conclusive results.

Having read and understood all information given to me and having asked all concerning questions, I ______ ACCEPT, _______ DECLINE the AFP screening test offered to me.

NAME _________________________________ DATE ________________

(Please Print)

SIGNATURE ______________________________________________ ___
Guide For Prenatal and Pediatric Counseling

An Honors Thesis (Honors 499)

by

Adam Hott

Thesis Advisor

Dr. William Rogers

(Signature)

Ball State University

Muncie, Indiana

May 5, 1999

Expected Graduation Date:

May 8, 1999
Down’s Syndrome Information Sheet

Down’s syndrome is a disorder caused by the genetic material in the child’s body being arranged improperly. The normal human body is composed of cells. Each cell contains genetic material arranged in a very specific order. A disruption in the order of how the genetic material is stored causes abnormalities.

Down syndrome results from an extra chromosome being inherited from either the father or the mother. A chromosome is a unit of genetic material. An extra copy of this genetic material causes characteristic changes in the person with Down’s syndrome.

The age of the mother is a crucial factor in the inheritance of this disorder. The higher the mother’s age, the higher the risk is for delivering a child with Down’s syndrome. Table 1 shows the risk associated with increasing age. Women of age 30 and greater show an increased risk for Down syndrome. Testing is recommended for women age 35 and greater. Normally test take between two and three weeks to return due to the complexity of the testing procedure.

Down syndrome has been described by a set of symptoms that are seen in persons with Down syndrome. Some of these characteristics are noticeable early in life however most are not able to be determined until later in life. The average life span of a person with Down syndrome is 20-25 years old. Some characteristics noticeable early in life are listed below.

- Hypotonia
- Poor Moro Reflex
- Hyperflexibility of Joints
- Excess Skin on Back of Neck
- Flat Facial Profile
- Slanted Palpebral Fissures
- Anomalous Auricles
- Dysplasia of Pelvis
- Dysplasia of Midphalanx of Fifth Finger
- Simian Crease
- Protrusion of Tongue
Glossary for Down Syndrome

Anomalous - Irregular, deviating from normal.

Auricles - Outside portion of the ear.

Dysplasia - Abnormal development of tissue.

Facial - Pertaining to the face.

Fissure - A groove or natural division.

Hyperflexibility - Having extreme flexibility, particularly in the legs and arms.

Hypotonia - A reduction of tension, especially in muscles.

Midphalanx - The middle bone of the finger.

Moro Reflex - A reflex seen in infants in response to a variety of stimuli, such as movement or the surface on which the infant rests, blowing in the face, or tapping the abdomen. Normally the infant responds by rapid abduction and extension of the arms followed by an embracing motion of the arms.

Palpebral - Pertaining to the eyelid.

Pelvis - Bones of the hips and rump.

Protrusion - State of being thrust forward or sticking out.

Table 1:
Estimate Risk of Live Births of Babies With Down syndrome for Maternal Age 15 to 50

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DOWN SYNDROME SUPPORT ASSOCIATION OF SOUTHERN INDIANA, INC.
Ann Steiner
3215 Chipoway Court
Floyds Knobs, IN 47119
812-923-5026

DOWN SYNDROME ASSOCIATION OF SOUTHEASTERN INDIANA
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812-934-4697

DOWN SYNDROME FAMILY SUPPORT GROUP AND ADVOCACY GROUP
Anne McGraw, Parent Phone Contact Only
317-233-1671

Bonnie Hay, Parent Phone Contact Only
219-272-9591

R.O.S.E.B.U.D.S. (REGIONAL ORGANIZATION FOR THE SUPPORT, EDUCATION AND BETTER UNDERSTANDING OF DOWN SYNDROME)
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Cinde Steele
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Lafayette, IN 47905
317-448-6299

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Newburgh, IN 47629
812-853-7628
DOWN SYNDROME SUPPORT GROUP - ELKHART COUNTY
Kelly Himes
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Elkhart, IN 46514
219-266-1463

DOWN SYNDROME SUPPORT GROUP OF CENTRAL INDIANA
Larry and Karen Kaser
10792 Downing Street
Carmel, IN 46033-3869
317-574-9757

DOWN SYNDROME SUPPORT GROUP - VIGO COUNTY
Debra J. Hills
1318 S. Center Street
Terre Haute, IN 47802
812-235-1367
Spina Bifida Information Sheet

Spina Bifida is tested for with the AFP test. Increased levels in the AFP test may suggest that Spina Bifida or anecephaly is a possibility. Spina Bifida is a fault in the spinal cord development. This fault is caused by the vertebrae of the backbone not forming together correctly causing a gap or hole. There are three basic types of Spina Bifida: Occulta, Cystica and Cranium Bifida.

**Spina Bifida Occulta**

The prevalence of this type of Spina Bifida is great, possibly as high as 5-105 of the population. It usually results in a small hole in the lower back. It can be found by X-ray of the back. To most of the people with Spina Bifida Occulta, there are few symptoms and problems. One of the problems that may occur with this type of Spina Bifida is loss of bladder control and mobility due to the nerve having excess pressure on it from the spinal column. Women with this type of Spina Bifida are encouraged to take higher dosages of folic acid during pregnancy to help reduce the risk of their baby being affected.
**Spina Bifida Cystica**

Spina Bifida Cystica is more detrimental. This type results in a cyst or blister-like growth on the back covered by a thin layer of skin. The spinal cord may actually grow out into this pouch and therefore may be exposed to increased risk of damage. The spinal cord involved in this is often damaged or not properly developed. The damage results in varying degrees of paralysis, loss of sensation, and bowel and bladder control loss. Most often these are directly related to the position of the cyst.

**Cranium Bifida**

Cranium Bifida is the most severe form. The bones of the skull fail to develop properly causing a sac to form called a encephalocele. This sac may contain cerebro-spinal fluid and tissue only or a part of the brain causing severe brain damage. The most severe forms of this type are iniencephaly and anencephaly. The brain does not form at all or does not form properly in this form and the child is usually stillborn or dies shortly after delivery.
HIV Test
PATIENT INFORMATION FORM

Indiana law requires that prenatal care providers primarily responsible for your pregnancy care offer you information and counseling about human immunodeficiency virus (HIV) and offer you an HIV test. The Indiana State Department of Health and health care professionals strongly recommend that all pregnant women be voluntarily tested for HIV during their pregnancy. Medical studies show that if you are infected with HIV, you could decide to take medicine during your pregnancy that will decrease the chance of your baby getting HIV during your pregnancy or at the time of delivery. It has been proven that this medicine can prevent infection in two out of every three babies who would have been infected.

To meet the requirements of the law, you must read or have read to you this form, discussed it with your prenatal care provider, and sign it. Upon completion the form will be placed in your medical and/or office record.

I am being given information about HIV to help me understand why it is important to have an HIV test during my pregnancy.

I also know that to protect both my child and myself I should share my HIV test results with my prenatal care provider.

➢ What are some facts about HIV and pregnancy?
  - People may not know they have HIV because they may feel well.
  - HIV is found in blood, semen, vaginal fluids and breast milk.

➢ How can HIV be passed from person to person?
  - HIV can be passed through high-risk behaviors such as unprotected sex with someone who is HIV positive and sharing of needles.
  - HIV can be passed through blood transfusions.
  - HIV can be passed to an unborn child during pregnancy, during delivery, and after birth through breastfeeding.

➢ How can I reduce my risk of becoming HIV infected and how I can reduce the risk of passing HIV to someone else if I am HIV positive?
  - Avoid high-risk behaviors (unprotected sex with someone who is HIV positive and sharing needles) that are proven to transmit HIV.

➢ What are my choices?
  - I understand that I can choose whether or not to be tested for HIV.
  - If I choose to be tested, I can be tested either confidentially through my prenatal care provider's office, a hospital or a laboratory, or anonymously, through referral to a state supported counseling and testing site.

Referral information about HIV prevention and psychosocial services, if needed, including anonymous and confidential test sites approved by the Indiana State Department of Health, was offered and discussed with me. Indiana law requires that all confidential positive test results be reported to the Indiana State Department of Health. I further understand that if I am tested confidentially the report to the Indiana State Department of Health will include my name and other identifying information. I also understand that confidentiality laws protect this personal information about me.
The following information is important for me to understand concerning an HIV test:

- The HIV test:
  - Is a test for HIV antibodies to the virus and not a test for the disease called AIDS.
  - If positive, means that my body has made a substance in reaction to the virus.
  - If positive, means that I probably have HIV that could be passed to other people including my newborn baby.

- The benefits of getting an HIV test include:
  - If positive, I can choose to get medical treatment for myself and my child.
  - If positive, I can take medicine prescribed by my doctor to decrease the risk of giving my baby HIV.
  - If negative, I can keep myself from becoming HIV positive by avoiding high-risk behaviors.

- The risks of an HIV test include:
  - There is a small chance that a test could be wrong.
  - A negative HIV test result doesn't always mean that I am HIV negative. My body may not have had time to produce the antibodies against HIV that the test measures. It takes between 6 and 14 weeks to make enough antibodies to make the test positive. Therefore, if I engaged in a high-risk behavior at any point up to 14 weeks before the first test was done, a follow-up test should be taken to verify the negative test result.
  - To help ensure the accuracy of my HIV status, I should not engage in behaviors that put me at risk for HIV between the tests.

Read carefully and check all appropriate statements, and sign.

___ I have read and understand the information provided about HIV and the HIV test. If I am unable to read and understand this information, my health care provider has explained this information to me.

___ I give my consent to have my blood drawn for the HIV antibody test. I understand that my HIV test result is confidential and I consent to my health provider's sharing of the information concerning my HIV status with other health care providers that provide me with medical treatment throughout my pregnancy and delivery. Indiana law requires that a positive test result be confidentially reported to the Indiana State Department of Health. OR

___ I decline the offer of the HIV antibody test.

_________________________                         ________________________
Signature of Patient                                   Date

This document when placed in the women's medical record, meets the requirement of the law.
HIV Counseling Guide

HIV is a serious illness that not only affects the mother but also has been shown to have dramatic effects on a fetus and residual effects on that infant once born. During the early 1990's, an estimated 1,000 to 2,000 infants were born with HIV. Because of increased knowledge about this disease and how it is contracted, further research has lead to the awareness of mother-to-child infection. The number of infants born with HIV has decreased dramatically in the last few years due to the incorporation of education and prenatal medication as a routine medical procedure.

The patient information form addresses some of the FAQ's associated with both HIV and the test.

- Facts about HIV
  - HIV can go undetected due to no noticeable health problems
  - HIV is found in the blood, semen, vaginal fluid, and breast milk
- Passing HIV from person to person
  - May be passed through unprotected sex, sharing needles and other sexual contact involving exchange of bodily fluids with an individual which is HIV positive
  - May be passed through blood transfusions -- this is rare in recent years due to extensive screening of the blood by the Red Cross
  - May be passed to an unborn child during pregnancy, during delivery and after birth through breastfeeding

Passing HIV to an unborn child during pregnancy is possible through the exchange of blood from the mother to the fetus. If the mother’s blood contains HIV, the child has an average risk of 25% of contracting HIV. Due to prenatal education on HIV and medicinal intervention, the rate of mother-to-child transmission has dropped dramatically. The recommended treatment to decrease the risk of mother-to-child transmission recommended by the Public Health Service is a combination therapy of antiretroviral drugs as well as protease inhibitors (PIs), substances that bind and inhibit enzyme action. Considerations for use of antiretroviral drugs during pregnancy are: 1) the possible need to change dosage as a result of changes associated with pregnancy 2) the potential of adverse short- or long-term effects on the fetus and newborn 3) the effectiveness for reducing the risk for perinatal transmission. The patient should be educated about the risks involved in the drug therapy. The possibilities of any and all of the following happening have only been shown in a small number of studies and with small sample sizes. Studies on the risks of using combination drug therapy are still underway and have some conflicting results. The patient should be aware that women on combination therapy were reported to have had higher than expected rates of premature births however this has not been directly correlated to the women’s use of HIV therapy. A study done by the NIH identified a greater than expected number of premature births among HIV-infected pregnant women who were participating in two of three studies of PI-containing combinations of antiretroviral drugs. A study from Switzerland of 37 pregnant women with HIV, 16 of which were on combination therapy including 1 or 2 PI’s, showed that 21 of the 37 had adverse reactions. Most commonly these reactions included
anemia (41%) and premature births (33%). The cause of the premature births and birth defects among HIV-infected women who are on combination therapy is not known. The severity of the HIV illness is thought to also contribute to the likelihood of prematurity. Combination therapy including the use of PI’s during pregnancy was also mentioned as a risk factor for gestational diabetes. The use of combination drug therapy and education of risks to pregnant women has shown a decline of perinatally acquired AIDS cases of 43% from 1992 to 1996. The decline of cases is continuing and is expected to continue into the future. The combination of education and medical intervention continually shows progress in decreasing the number of AIDS born children.

- How can they reduce the risk of becoming HIV infected and how can they reduce the risk of passing HIV to someone else if they are HIV positive?
  Avoid high-risk activities such as unprotected sex with someone who is HIV positive and sharing needles.
  Inform and become informed about their partner.

- What are the patients choices?
  They have the right to choose whether or not to be tested for HIV
  They have the choice to be tested either confidentially through your prenatal care provider, a hospital or laboratory, or anonymously, through referral to a state supported counseling and testing site.

- The HIV test
  The HIV test is a test for HIV antibodies to the virus. It is not a test for the disease AIDS
  If the HIV test is positive, it means that the patients body has made antibodies against the virus
  If the HIV test is positive, it also means that most likely the patient has HIV and is able to pass the virus on to another person or to a fetus or newborn.

- Benefits of HIV test
  Medical treatment is available for both the patient and the child.
  Medical treatment taken can reduce the risk of passing HIV on to the patient’s fetus or baby
  If negative, education about the risks of HIV help to keep the patient from contracting HIV.

- Risks of HIV test
  Small chance that the test could be wrong.
  A negative test does not mean that the patient does not have HIV. Antibodies to HIV take between 6 and 14 weeks to accumulate to high enough levels in the body to be detected. A follow-up test should be done on HIV negative results.
Group B Streptococcus
Group B Streptococcus Information Sheet

Group B Streptococcus (GBS) is a bacterial infection that is most prominent in the rectum and vagina of women. It is estimated that as high as 40% of women are carriers of the bacterial colony during pregnancy. In most women, the colonization will not cause any harm to the mother or child. It has been reported that 98-99% of all babies that were born from colonized mothers showed no infection after birth. For those infected, only a few will have any problems with the infection. There are two types of infections one may contract: Early and Late.

**Early Infections**

Early infections tend to occur very soon after birth, within the first six hours. At the latest, most early infections will occur by the seventh day. This type of infection may cause inflammation of the child’s lungs, spinal cord, or brain. In about 15% of infected babies, the infection will be fatal.

**Late Infections**

The late infections occur after the first seven days. Only about 50% of the infections of this type are contracted from the mother. It may be contracted from other carriers of the GBS infection in which the child is in contact. The main risk for children who contract late infection GBS is meningitis. Meningitis can develop long term problems associated with the child’s nervous system. Late infections are less likely to become fatal than early infections, however long term effects may be more severe.

**Risk Factors and Testing for GBS**

Detection of risk factors along with testing is the most efficient way to stop infection of the child. Risk factors of a GBS infection include previous child colonized with GBS, preterm birth at less than 37 weeks, intrapartum fever of greater than 100.4°F, and premature membrane rupture during labor lasting more than 18 hours. Testing is simple and generally painless. It involves a swab culture being taken from the vagina and/or rectum of the mother during pregnancy, usually done at 35-37 weeks. A urine screen may also be used as a testing procedure. Screening done before 35-37 weeks is not an accurate test for predicting who will be infected or colonized at the time of delivery. Testing will only show a positive result if the vagina or rectum is colonized at the time of testing. The false negative percentage runs between 10-20%.

**Treatment**

There are two general types of treatments for prevention of GBS infections: oral antibiotics and IV antibiotics during labor. Oral antibiotics have not been recommended for treatment by any of the professional organizations. However, at the end of pregnancy oral antibiotics may be given to reduce the number of colonies in the body. This has not been shown to be an effective form of prevention for infection of a newborn. The IV treatment is the most widely used treatment and has been shown to decrease the onset of GBS in newborns in 70-85% of the cases.
FAQ's

• **How did I get it?**
  GBS is a naturally occurring bacteria in the body. It is possible that the bacteria can be transmitted sexually to and from your partner.

• **Can I still breast-feed if I have GBS?**
  Yes. A child will not contract GBS through breast milk.

• **Would a cesarean prevent transmission to the baby?**
  No. There have been documented cases that the infection is contracted through cesarean and through vaginal birth.
Group B Streptococcus Quick Sheet

General Information
- GBS is a bacterial infection of the rectum and vagina
- Colonization does NOT USUALLY cause any harm to mother or child

Early Infections
- Early infections in children occur usually in the first 6 hours and no later than the 7th day of life
- Early infection may cause inflammation of child’s lungs, spinal cord, or brain
- 15% fatality of infected children

Late Infections
- Late infections in children occur after the first seven days of life
- Main risk for late infection is meningitis
- Late infections are less likely to be fatal but have more severe long-term affects

Treatment
- GBS can be treated either through oral antibiotics or through IV antibiotics during labor
Rh Factor Incompatibility
Rh Factor Incompatibility Information Sheet

Rh factor is a chemical that is found in the blood and is one of the components that determine blood type. The Rh factor is a chemical found on the outside of the blood cells. The body's natural response to any chemical on the outside of the cell that it does not recognize, is to eliminate the cell from the body by killing it. This causes the problem with Rh factor incompatibility.

The presence of the Rh factor in the blood is given by the positive or negative blood type of the individual. For example: If an individual has the blood type A-, the Rh factor is not found in the blood → the negative sign showing that there is no Rh factor present. If an individual has the blood type of A+, the Rh factor is found in the blood → the positive sign showing that there is Rh factor present on the outside of the cell.

Risk
Rh incompatibility is only a concern if the mother has Rh negative blood, shown by the blood type with a negative symbol after it (i.e. A-, B-, AB-, O-), and has had a child with Rh positive blood, given by the blood type with a positive symbol after it (i.e. A+, B+, AB+, O+), or has had a blood transfusion with Rh positive blood. Rh incompatibility will only affect future pregnancies and will not have any effect on the mother. Furthermore, future pregnancies are only at risk if the unborn child is Rh positive.

Complications
Complications from Rh incompatibility can arise and may be severe. Future pregnancies are at risk of severe anemia during pregnancy. This means that the mother's body is effectively destroying the unborn child's blood cells. This may cause severe effects on the child's development such as improper brain and spinal cord formation which can lead to mental retardation and other neurological problems.
**Treatment**

Rh incompatibility does not have to be a problem if it is treated with a specific drug called RhoGam. RhoGam is administered after delivery of the first child to prevent the mother from creating the chemicals that are the cause of the complication for future pregnancies. If the RhoGam was not administered after the first pregnancy, during the second pregnancy, where Rh factor incompatibility is a possibility, it should be administered during the 28th week. This will decrease dramatically the risk of complications associated with Rh factor incompatibility. If the mother is Rh negative and the unborn child is Rh positive in any pregnancy, the mother should also receive RhoGam if the mother has had bleeding during pregnancy or has had an amniocentesis. These two things increase the risk of blood transfer from mother to child and may cause the same ill effects as Rh incompatibility in future pregnancies.

The only exception to having the RhoGam is if the child is not at risk for Rh incompatibility. The child is not at risk only if both the father and mother are Rh negative. This means that the child will also be Rh negative and there will not be Rh incompatibility. If the father, however is Rh positive or of unknown blood type, then the RhoGam is needed.
Rh Factor Incompatibility Quick Sheet

General Information
• Rh factor is found on red blood cells

• Rh incompatibility problems are caused by the body's natural response to a foreign chemical, Rh factor, on the outside of the red blood cells

• Rh factor presence is given by the positive or negative symbol on the blood type (i.e. A+, B-)

Risk
• Concern if the mother is Rh NEGATIVE and the unborn child is Rh POSITIVE

• Concern if the mother has had a blood transfusion with Rh positive blood

• Risk is only for future pregnancies not current, first time pregnancies

Complications
• Risk of severe anemia

• Anemia may cause damage to brain and spinal cord development which may lead to mental retardation or other neurological problems

Treatment
• Treatment with RhoGam after delivery of first pregnancy is best treatment

• If RhoGam was not given after delivery of first pregnancy, RhoGam should be given during 28th week of future pregnancies

• Only exception to RhoGam is if the father's blood type is known to be Rh negative
Ethnicity Risks
Ethnicity plays an important role in the prevalence of many disorders. In many populations around the world there are higher risks for certain disorders than in other populations. This is highly due to the fact that people of a certain culture or ethnic background tend to stay within that culture or ethnicity when choosing a partner. This type of selection carries with it the increased risk of passing down disorders in a larger frequency of births. With better communication technologies and more knowledge about other cultures, this type of information is becoming more available.

Jewish Populations
One of the most common disorders in the Jewish population is Tay Sachs disease. Both are genetically inherited and are seen in a higher frequency in the Ashkenazi Jewish population than in any other population. Tay Sachs disease is a progressive neurodegenerative disease. This means that it slowly destroys the brain’s and nerves’ ability to function properly. Tay Sachs disease is caused by a deficiency in a chemical normally produced by the body. Symptoms are usually first noticed as early as six months. This disorder is lethal resulting in the death of the child usually between the ages of five to eight years old.

Canavan disease is another disorder that plagues the Ashkenazi Jewish population. It is also a neurodegenerative disease and is also lethal. Usually the disease is characterized by developmental delay, poor muscle control and a large head. Canavan disease is also the result of the body’s inability to produce a chemical, different from that of Tay Sachs disease, that is needed for proper development. At birth children appear normal, but slowly degenerate. Usually children affected by Canavan disease die by the time they are teenagers. Neither Tay Sachs or Canavan disease are treatable or curable.
Testing
There has been a test developed for these two disorders. It is called the Ashkenazi Jewish Genetic Diseases Screen. It screens for Tay Sachs, Canavan and cystic fibrosis. The screening test may be done before birth by amniocentesis, but is not a common practice. The more common screening test is for the parents-to-be. This test shows if the mother and father are carriers of the disease genes and in both diseases has been found to be over 97% accurate.

Inheritance
Both Tay Sachs and Canavan disease are inheritable and have their origins in the mother and father’s genes. Both diseases are inherited by a process known as autosomal recessive inheritance. This means that a child with Canavan or Tay Sachs disease must have inherited a recessive gene from both the mother and the father. The mother and father are then termed carriers of the gene. Neither the mother or the father may show any signs of these diseased genes because they are not expressed due to the normal gene being present also in their body. If the mother and father are tested for these disorders and are found to be carriers of the disorder, there is a 1 in 4 (25%) chance that the child will have the disease and a 3 in 4 (75%) chance that the child will be unaffected.

American White Population
Another common disease that has an increased frequency in the American white population is cystic fibrosis (CF). CF has many ill effects on a child including pulmonary and gastrointestinal abnormalities (i.e. lungs and intestine). It affects 1 out of 2500 people in the American white population which includes the Jewish population as well.

Inheritance
Cystic fibrosis is inherited much like Tay Sachs and Canavan disease is. It is inherited through a pattern called autosomal recessive inheritance. Like Tay Sachs and Canavan disease, a mother and a father can be carriers of the gene and not know it because they do not suffer from the disorder themselves. The occurrence of carriers in the American white population is about 1 in 25.
Testing
Screening for CF is a possibility through the Ashkenazi Jewish Genetic Diseases Screen. This test, used for Canavan disease and Tay Sachs disease, has been found to be about 90% accurate in the American white population. The effectiveness of this test is limited by the nature of the disorder. The gene that this disease is related to has over 500 different forms all causing the same symptoms of CF. This makes it impossible to test for all 500 forms. The 30 most common forms are tested for. In Hispanic-American populations, however only about 60% of the carriers can be found through this test.

African American and Mediterranean American Populations
These two populations are at increased risk for diseases of the blood called hemoglobinopathy. One of the most common diseases of this type is Sickle cell anemia. This disease is caused by a malformation of the red blood cells in which they take on the appearance of a sickle. The shape of the cell does not allow it to properly flow through the body and causes ill affects such as increased susceptibility to infection, chronic anemia, and painful crises.

Inheritance
Sickle cell anemia is also inherited in an autosomal recessive inheritance pattern. Carriers of the gene can pass it along to their child. The carrier form of the disease does not seem to have any affect on the individual.

Testing
Testing is available for sickle cell anemia. It can be done before birth through amniocentesis. Testing is also available during the newborn period. The test looks for one changed gene in the child. Because sickle cell anemia is controlled exclusively by this one gene it makes the test fairly simple.
<table>
<thead>
<tr>
<th></th>
<th>Tay Sachs</th>
<th>Canavan Disease</th>
<th>Cystic Fibrosis</th>
<th>Sickle Cell Anemia</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Frequency of Carriers</strong></td>
<td>No Information</td>
<td>No Information</td>
<td>1 in 25 Caucasians</td>
<td>1 in 10 African Americans</td>
</tr>
<tr>
<td><strong>Frequency in Population</strong></td>
<td>No Information</td>
<td>No Information</td>
<td>1 in 2500 Caucasians</td>
<td>No Information</td>
</tr>
<tr>
<td><strong>Life Expectancy</strong></td>
<td>5-8 Years</td>
<td>Early Teens</td>
<td>Usually before age 30</td>
<td>Normal life span but with many difficulties and large need for medical treatment</td>
</tr>
<tr>
<td><strong>Testing</strong></td>
<td>Ashkenazi Jewish Genetic Diseases Screen</td>
<td>Ashkenazi Jewish Genetic Diseases Screen</td>
<td>Ashkenazi Jewish Genetic Diseases Screen</td>
<td>Prenatal test through amniocentesis and newborn test available through blood work</td>
</tr>
</tbody>
</table>
Phenylketonuria, (PKU), is an inherited metabolic disease that may result in mental retardation and other neurological problems when treatment is not started within the first few weeks of life. With proper treatment and a regulated diet, PKU can be controlled and PKU sufferers can live a healthy normal life. PKU arises from the absence of a single chemical that normally functions to help make other chemicals needed for proper development of the brain and nerves.

**Inheritance**

PKU is passed along through an autosomal recessive gene. This means that in order for a child to inherit PKU, both the mother and the father must either have PKU or be carriers of the gene. It is possible that the mother and father are not aware that they are carriers and therefore have the possibility of passing that gene onto the child. The approximate incidence rate of being a carrier of the PKU gene is about 1 in 50 people. PKU screening is a standard procedure for newborns in every state in the US and in many other countries.

**Treatment**

PKU is treated by a special diet that regulates protein intake. PKU is easily controlled by this diet. Stopping the diet can result in serious problems including drops in IQ, learning disabilities, behavior problems such as hyperactivity and irritability, and neurological problems such as tremors, eczema (a skin disorder), and personality disorders.

A normal range of phenylalanine level is about 2-6 mg/dl. This has been shown to be the safest range of levels. Blood monitoring should be done in order to insure that this level stay within it normal and safest range. A structured diet is the best way to keep this level safe. Any individual with PKU is advised to return to the diet if they have stopped for any reason.

Pregnant women with uncontrolled PKU (not controlled by diet) are at extreme risk for harming their unborn child. Women returning to the diet before conception and keeping PKU under
control has been shown to dramatically reduce the risk of harming the unborn child. Controlling PKU is not only important for the safety of the unborn child but also for the safety and health of the mother. All children born with PKU should be followed by a specialized PKU program with satisfactory monitoring devices that are available in every state of the U.S.
**PKU Quick Sheet**

**General Information**
- PKU (Phenylketonuria) is inherited and may result in mental retardation and neurological problems
- PKU can be controlled throughout life
- PKU is caused by the absence of phenylalanine hydroxylase that changes phenylalanine to another needed chemical

**Inheritance**
- Autosomal recessive inheritance
- 1 in 50 people are carriers of recessive gene (heterozygous individuals)
- PKU screening is standard procedure in all 50 states

**Treatment**
- Treatment is done through diet
  - A special diet should be maintained throughout life of regulated protein intake
  - If the diet is not followed throughout life, it may result in drops in IQ, learning disabilities, behavior problems, and neurological problems such as tremors, eczema, and personality disorders.
  - A normal range of phenylalanine should be maintained at about 2-6 mg/dl

**Risks**
- Pregnant women with PKU that is not controlled by diet may cause severe damage to their unborn child
- All individuals with PKU are at risk for a variety of problems throughout life if it is not controlled
Fetal Alcohol Syndrome
Fetal Alcohol Syndrome Information Sheet

Fetal alcohol syndrome is caused solely by the intake of alcohol by the mother during pregnancy. Fetal alcohol syndrome may cause some severe affects on the unborn child. Mental retardation is the most common occurrence among fetal alcohol syndrome children. All problems associated with fetal alcohol syndrome are permanent and can be very costly to treat if treatment is available.

Cause
Fetal Alcohol Syndrome is the leading known cause of mental retardation. It produces irreversible physical and mental damage. Fetal alcohol syndrome is caused by consumption of alcohol by the mother during pregnancy. There is no safe level of alcohol consumption during pregnancy. One drink is sufficient to cause severe damage. The first trimester is the most crucial stage and the hardest to control alcoholic intake at. It is difficult to control alcoholic intake because many women do not know that they are pregnant until after the first month. Damage from alcohol intake may have already occurred. Alcohol is so detrimental to developing fetuses because alcohol is taken in by all organs in the mother’s body and the placenta. The child is then passed on the alcohol directly. The undeveloped liver of the child cannot process the alcohol well. It can take up to three times as long for the unborn child’s liver to process the alcohol than it would for the mother’s fully developed liver. Fetal alcohol syndrome is 100% preventable by excluding or at least limiting the alcohol intake by the mother during pregnancy or in preparation for pregnancy.

Complications
There are two degrees of alcohol related damage that can occur: Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE). Both degrees of damage are very detrimental but FAE tends to be more mild than FAS. Early exposure to alcohol presents the greatest risk for serious physical defects including small head size, a flat midface, narrow eye slits, muscle problems, bone and joint problems, genital defects, heart defects, and kidney defects. The brain size can also be
affected at this time decreasing the size of the brain significantly. Late exposure increases the chance of miscarriages, neurological and growth deficiencies. The highest risk for miscarriages occurs during the second trimester. During the third trimester, growth impairment and brain and central nervous system damage is most prominent.

Inheritance
FAS and FAE are not genetic (inherited) disorders. There is no known gene for alcohol consumption and all cases of FAS and FAE can be prevented by eliminating alcohol consumption during pregnancy. FAS occurs in about 1 out of 750 live births. FAE occurs in about 36,000 births each year, about 10-12 out of 1,000. Parental influences on FAS and FAE include social habits and male influence on the female’s alcohol consumption.

Treatment
There is no treatment for FAS or FAE. The damage is permanent and will affect the child throughout his or her life. Many schools have special programs to work with children with learning disabilities which may help to some degree. Surgical procedures can be done to help the physical problems. Neurological drugs may help to some degree also. These usually are most helpful with behavior disorders. Treatment is limited because the damage was done during development and cannot be fixed once it has been inflicted.
Fetal Alcohol Syndrome Quick Sheet

**General**
- Fetal Alcohol Syndrome is 100% preventable
- FAS is caused by the consumption of alcohol during pregnancy

**Cause**
- Any amount of alcohol is enough to cause FAS
- An unborn child cannot process the alcohol well due to an undeveloped liver
- Alcohol can cross the placenta

**Complications**
- Most common complication is mental retardation
- Serious physical defects such as small head size, flat midface, narrow eye slits, muscle problems, and heart defects are among the many that are associated with FAS

**Inheritance**
- FAS is not inherited
- The sole cause is consumption of alcohol during pregnancy

**Treatment**
- The only treatment is PREVENTION
- Hardest to prevent during first trimester because some do not know they are pregnant
- Best to eliminate or at least limit amount of alcohol intake during pregnancy or in preparation for pregnancy
Genetic Counseling Information
What is Genetic Counseling?

Genetic Counseling is the explanation of technical and complicated genetic knowledge into practical information.

Genetic Counselors are health care professionals with specialized training in medical genetics and counseling. Genetic counselors are certified by the American Board of Genetic Counseling.

Goals of Genetic Counseling

Help the individual or family:
- understand the medical facts including the diagnosis, prognosis, and available treatment
- comprehend hereditary patterns and recurrence chances
- understand the options for testing
- adjust to the information provided

What Happens in a Genetic Counseling Appointment?

Step by Step

Genetic counselors may:
- ask questions about your medical history
- draw a picture of the "family tree"
- recommend laboratory testing or other procedures
- review the chance for having another affected individual in the family
- discuss reproductive options, carrier testing, and treatment options
- provide or refer for psychosocial support
- refer to other medical specialists and community resources

Plan to spend approximately one hour at your first visit. Additional visits may be necessary to review test results and address other family concerns. A summary letter of the visit will be sent to the family and referring physician.

Who Should be Offered Genetic Counseling?

Individuals or families are often referred to the Genetic Counseling Clinic by a family doctor or specialist for the following reasons:

When a child or individual has
- a genetic syndrome or trait
- a chromosomal condition
- a hereditary birth defect

When a couple has
- multiple pregnancy losses
- a miscarriage with a chromosome problem or other birth defects
- concern about medications, drugs, chemical exposures, or a mother’s health during pregnancy
- an ethnic background associated with a genetic disease

When there is a family history of
- birth defects, genetic syndromes or chromosomal conditions
- mental retardation or certain neurological disorders
- spina bifida, anencephaly or other defects of the brain or spinal cord
- a particular condition such as cystic fibrosis, muscular dystrophy, or Down syndrome

Genetic Counseling is a Service of the Department of Medical and Molecular Genetics
Indiana University Medical Center
975 West Walnut Street
Indianapolis, Indiana 46202
When You Visit a Genetic Counselor

Preparation

Please bring as much information about your family history as possible. Photographs and baby books of family members who have physical traits that "run in the family" are often helpful. Please obtain all pertinent medical records and send them prior to your appointment.

Billing

Preauthorization by a primary care physician is required by most healthcare plans. Fees will vary depending on the complexity of the session. Additional charges may be incurred if special testing is indicated. Prior to your appointment, the registration office should contact you to obtain insurance and pre-approval information. Please bring insurance information to your appointment as well. Billing for services will appear in the name of the Director of Clinical Services, David D. Weaver, M.D. or one of his associates.

Clinic Personnel

Certified Genetic Counselors
Lola P. Cook, M.S.
Emily Lichtenberg, M.S.
Susan S. Romie, M.S.

Physician Geneticists
David D. Weaver, M.D.
Wilfredo Torres, M.D.

Where To Go for Genetic Counseling

Appointments

Appointments may be scheduled by calling Iris Pettigrew at (317) 274-1057. Individuals without an established diagnosis will be referred to the Medical Genetics Clinic for evaluation and counseling. Individuals with a family history of cancer should contact Cindy Hunter, genetic counselor for the Indiana Familial Cancer Clinic, at (317) 274-3060.

Location

The Indiana University Medical Center is located on the west side of Downtown Indianapolis. Please see a campus map for directions and parking information. Proceed to the Medical Research Library Building at 975 West Walnut Street (near University and Riley Hospitals). The Department of Medical and Molecular Genetics is on the first floor. Notify the receptionist of your genetic counseling appointment.

Genetic Counseling Services

Information for You and Your Family

Your Appointment

Date________________________ Time________________________

Notes:

This project is supported in part by Title V, Maternal and Child Health Block Grant funds administered through the Indiana State Department of Health, Maternal and Child Health Services.
Service Providers

Lola Cook, M.S.
Genetic Counselor and Indiana Teratogen Information Service Coordinator

Wilfredo Torres, M.D.
Clinical Assistant Professor of Medical and Molecular Genetics

David D. Weaver, M.D.
Director of the Indiana Teratogen Information Service and Professor of Medical and Molecular Genetics

Indiana Teratogen Information Service

Hours

Call Monday - Friday
9 A.M. to 5:00 P.M.

317-274-1071
to speak to a Genetic Counselor

For after-hour emergencies, call the Indiana University Medical Center operator at 317-274-5000, and ask the operator to page the on-call clinical geneticist.

www.medgen.iupui.edu/

Lola Cook

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Department of Medical and Molecular Genetics
Indiana University Medical Center
975 West Walnut Street
Indianapolis, IN 46202
What is a Teratogen?

A teratogen is any medication, chemical, infectious disease, or environmental agent that could interfere with the development of the fetus. The result may be loss of the pregnancy, a birth defect, or pregnancy complications.

Common teratogens may include:

- prescribed or over-the-counter medications or vaccinations
- diseases or infections
- exposure in the workplace, at home, or in the community to chemical agents such as paints, varnishes, and pesticides
- exposure to physical agents such as excessive heat or radiation
- excessive consumption of agents known or suspected of being harmful to the developing baby such as alcohol, tobacco, caffeine, vitamins or illicit drugs

What is the Indiana Teratogen Information Service?

The Indiana Teratogen Information Service (INTIS) is a telephone inquiry service, available to:

- physicians
- nurses
- midwives
- other health professionals caring for pregnant women
- women who are already pregnant
- women thinking about becoming pregnant

The INTIS provides central, up-to-date, information from computerized sources, professional articles and expert consultants. Also available is lactation information about an agent. Phone calls will be answered by a genetic counselor, in consultation with Dr. David Weaver or other geneticists, in the Department of Medical and Molecular Genetics at the Indiana University Medical Center. There is no fee for this service.

What Information Do You Need to Provide?

- Exact name of the medication, drug, disease, type of X-ray or other agent of concern
- Exact dose, if possible (how many tablets, what strength, how much alcohol, how many shots, how many X-rays)
- Duration of the exposure (how many days medication was taken, how many times per week alcohol was consumed)
- Date(s) during which exposure took place
- Last menstrual period and current gestation of the patient
- Any family history of birth defects or genetic disease
- Maternal conditions and/or any major complications in the pregnancy