

**GENERAL INFORMATION**

Today's Date: \_\_\_\_\_

Child's Full Name: \_\_\_\_\_ Age: \_\_\_\_\_ Date of Birth: \_\_\_\_\_

Address: \_\_\_\_\_ City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Name of person completing this form: \_\_\_\_\_

Which X&Y Chromosome Variation (i.e. XXY, XYY, XXYY, XXX) does your child have? \_\_\_\_\_

Child Was diagnosed:  Prenatally  before age 5  age 6-11  age 12-18  after age 18

Approx. weight of child? \_\_\_\_\_ Approx. Height of child? \_\_\_\_\_

**CURRENT FAMILY SITUATION**

**Mother's** Name: \_\_\_\_\_ Age: \_\_\_\_\_ Education: \_\_\_\_\_

Relationship to Child:  Natural Parent  Step-Parent  Adoptive Parent  Foster Parent

Address: \_\_\_\_\_ City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Home Phone: \_\_\_\_\_ Cell Phone: \_\_\_\_\_ Work Phone: \_\_\_\_\_

Email Address: \_\_\_\_\_ Is email a reliable way to contact you?  Yes  No

**Father's** Name: \_\_\_\_\_ Age: \_\_\_\_\_ Education: \_\_\_\_\_

Relationship to Child:  Natural Parent  Step-Parent  Adoptive Parent  Foster Parent

Address: \_\_\_\_\_ City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Home Phone: \_\_\_\_\_ Cell Phone: \_\_\_\_\_ Work Phone: \_\_\_\_\_

Email Address: \_\_\_\_\_ Is email a reliable way to contact you?  Yes  No

With which parent(s) does the child live?  Both  Mother  Father  Other. \_\_\_\_\_

If Parents are separated or divorced, what year did this happen? \_\_\_\_\_ Who has custody of this child? \_\_\_\_\_

How often does the other parent see this child? \_\_\_\_\_

Do any other adults live in the home?  Yes  No If yes, Name, Age, Relationship: \_\_\_\_\_

How many other children are living in the home? (Please indicate if step-brothers/sisters or foster brothers/sisters)

Name and Age: \_\_\_\_\_

Name and Age: \_\_\_\_\_

Name and Age: \_\_\_\_\_

Name and Age: \_\_\_\_\_

Name and Age: \_\_\_\_\_

Is child adopted?  Yes  No If yes, Does child know they are adopted?  Yes  No

Age when child was first in home? \_\_\_\_\_ Date of Adoption? \_\_\_\_\_

**Doctor's** Name \_\_\_\_\_ Phone \_\_\_\_\_

Address: \_\_\_\_\_ City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_



**BIRTH INFORMATION**

Was infant born full term? Yes No If premature, how early? \_\_\_\_\_ If late, how overdue? \_\_\_\_\_  
Birth weight? \_\_\_\_\_ Type of Delivery? Vaginal Cesarean Twins  
Describe any complications during delivery: \_\_\_\_\_  
Infant's APGAR scores (if known): \_\_\_\_\_ 1 minute \_\_\_\_\_ 5 minutes

Did infant have:

Breathing problems after birth? Yes No  
Did infant require: Supplemental oxygen? Yes No  
Breathing tube & Ventilator? Yes No  
Did infant need bilirubin lights (for jaundice/yellow skin) Yes No  
Did infant have seizures? Yes No  
Did infant have bleeding into the brain? Yes No  
Did physician express concern about brain damage? Yes No  
Did infant require blood transfusions? Yes No  
Did infant require X-rays/CT scan/ultrasounds? Yes No  
Did the infant require the NICU (Neonatal Intensive Care Unit) Yes No

**PREGNANCY INFORMATION**

Mother's age during this pregnancy? \_\_\_\_\_ Father's age during this pregnancy? \_\_\_\_\_

Previous pregnancies? Yes No If yes, number of pregnancies (Including miscarriages, etc.) \_\_\_\_\_

Did mother receive prenatal care during the pregnancy? Yes No Starting in which month? \_\_\_\_\_

Did mother have any medical problems during or immediately before/after the pregnancy? (Vaginal infections, Urinary Tract Infections, Flus/Sore Throats, Seizures, High Blood Pressure, Diabetes, Premature labor, Anemia, Vaginal bleeding, Toxemia, Injuries, Emotional Problems?)

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Were any of the following used during this pregnancy? (check all that apply)

Medications. Please list: \_\_\_\_\_

Tobacco Marijuana Alcohol

Other (cocaine, amphetamines, methamphetamines, heroine, methadone, or specify): \_\_\_\_\_

Please list all other agencies and intervention services (e.g. speech therapy, OT, PT) involved with your family (e.g. Regional Center, Healthy Start, Child Protective Services, Early Intervention, etc.)

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**MEDICAL PROBLEMS/EVALUATIONS**

During this child's first 3 years, were any special problems noted in the following areas?

- Irritability
- Failure to thrive/poor growth & weight gain
- Difficulty sleeping
- Colic
- Difficulty feeding
- Excessive crying

If yes to any above, please describe: \_\_\_\_\_

\_\_\_\_\_

Does your child have other medical problems? Please check all that apply and explain, please include problems which have been treated in the past

- Ears? (Hearing problems, ear infections, etc.)
- Eyes? (Visual problems, strabismus, etc.)
- Dental? (Cavities, late tooth eruption, etc.)
- Neurologic Problems? (Seizures, tremors, brain malformations, abnormal muscle tone, etc.)

\_\_\_\_\_

Headaches? (Migraines, etc.)

Lung problems? (Asthma, lung disease, breathing problems)

\_\_\_\_\_

Cardiovascular/Heart problems? (heart defects, murmurs, irregular rhythm, valve problem, circulation)

\_\_\_\_\_

High or low blood pressure?

Stomach/Intestinal/Esophageal problems? (reflux/heartburn, ulcers, constipation, abdominal pain)

\_\_\_\_\_

Liver problems?

Genitalia/Urologic Problems? (undescended/small testicles, problems with urination, hernia, infections)

\_\_\_\_\_

Abnormal Pubertal development? (early, delayed or abnormal puberty, gynecomastia/breast enlargement)

\_\_\_\_\_

Thyroid problems?

Diabetes?

Orthopedic/Rheumatologic problems (Malformation of limbs/hands/feet, joint problems/pain, flat feet, etc.)

\_\_\_\_\_

Back problems? (scoliosis, kyphosis, other back abnormalities)

Skin or Hair problems? (rashes, skin ulcers/sores, birthmarks, etc)

\_\_\_\_\_

Allergies? (food, environmental, medications)

Blood problems (anemia, abnormal white blood cells, abnormal platelets)

\_\_\_\_\_

Frequent Infections? (skin, respiratory, urinary infections)

Has your child had any of the following diagnostic tests? (dates and results, if known)

EEG (brain wave test)

MRI

CT Scan

Blood Test (other than routine blood count)

Chromosomal/DNA testing

Vision Test

Other (specify) \_\_\_\_\_

\_\_\_\_\_

Which other types of medical specialists have seen and evaluated/treated your child?

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Please list all current medications and supplements:

Medication name:	Dose	How Often?
Medication name:	Dose	How Often?
Medication name:	Dose	How Often?

**FAMILY MEDICAL HISTORY**

**Mother:** Health, learning, mental health problems? Yes No If yes, please describe: \_\_\_\_\_

Medications currently taking? \_\_\_\_\_  
Number of Brothers: \_\_\_\_\_ Number of sisters: \_\_\_\_\_ Numbers of Nieces/Nephews: \_\_\_\_\_

**Father:** Health, learning, mental health problems? Yes No If yes, please describe: \_\_\_\_\_

Medications currently taking? \_\_\_\_\_  
Number of Brothers: \_\_\_\_\_ Number of sisters: \_\_\_\_\_ Numbers of Nieces/Nephews: \_\_\_\_\_

Are there any medical illnesses in other family members? (Please specify who)

- |  |  |  |
|--|--|--|
| <input type="checkbox"/> Birth defect                          | <input type="checkbox"/> Diabetes            | <input type="checkbox"/> Mental Retardation  |
| <input type="checkbox"/> Speech/Language delay                 | <input type="checkbox"/> High Blood Pressure | <input type="checkbox"/> Learning Disability |
| <input type="checkbox"/> Chromosomal disorder/genetic syndrome | <input type="checkbox"/> Seizures            | <input type="checkbox"/> Depression          |
| <input type="checkbox"/> Autism/PDD                            | <input type="checkbox"/> Kidney Disease      | <input type="checkbox"/> Anxiety Problems    |
| <input type="checkbox"/> Alcohol/Drug Abuse                    | <input type="checkbox"/> Cancer              | <input type="checkbox"/> ADD/ADHD            |
| <input type="checkbox"/> Other: (Please describe) _____        |  |  |

**Finding out about Sex Chromosome Aneuploidy – Prenatal Diagnosis**

Today's date: \_\_\_\_\_

Child's birth date: \_\_\_\_\_

Child's current age: \_\_\_\_\_

Which type of SCA does your child have? (47,XXY; 47,XXX; 47,XYY, etc): \_\_\_\_\_

1. How far along was your pregnancy when your child's diagnosis was made? \_\_\_\_\_

2. What type of prenatal testing identified your child's diagnosis (NIPT, blood test, CVS, amnio, etc)?  
\_\_\_\_\_

3. What was the reason you had prenatal testing performed (maternal age, abnormal ultrasound findings, no reason, doctor offered, etc)?  
\_\_\_\_\_

4. What doctor ordered your prenatal testing (routine OBGYN, maternal fetal medicine doctor, IVF doctor, etc)? \_\_\_\_\_

5. Were you told about the possibility of finding this diagnosis prior to testing? \_\_\_\_\_

6. Who provided you with information about the diagnosis? (routine OBGYN, maternal fetal medicine doctor, IVF doctor, genetic counselor, etc)?\_\_  
\_\_\_\_\_

7. Did you ever meet or speak with a genetic counselor or genetic doctor after getting the diagnosis? \_\_\_\_\_

8. How were you given information about the diagnosis? (in-person discussion, telephone conversation, written materials, etc)?  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

9. How much information was provided to you about the diagnosis when you were told?

0	1	2	3	4	5	6	7	8	9	10
Very Little					Adequate					A lot

What information was provided? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

10. In your opinion, was the provider who gave you information about the diagnosis well informed about the condition?  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

11. Was this diagnosis tested for and confirmed after birth / postnatally in your baby? YES / NO  If yes, were results the same? YES / NO \_\_\_\_\_

12. Other comments about your prenatal experience: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**X&Y CHROMOSOME VARIATION MEDICATION PROFILE – PART ONE - CURRENT MEDICATIONS**

PLEASE LIST THE MEDICATIONS YOUR CHILD IS CURRENTLY TAKING BELOW.

**#1) Medication Name** \_\_\_\_\_

Dose and Frequency of Medication (e.g. one 250mg tablet two times per day OR 250mg 3 times per day)

When was this medication started? \_\_\_\_\_ Which doctor started this medication? \_\_\_\_\_

Has the medication dosage been changed since the medication was started? Yes No

If yes, how has it changed? Why was it changed?

Why was the medication started? Which symptom(s) or problem(s) is the medication intended to treat?

Has the medication helped these symptoms?

Yes – the symptoms are significantly improved

No – the symptoms are the same

Yes – the symptoms are slightly improved

No – the symptoms are worse than before starting the medication

Please explain your answer above:

Does this medication have any side effects in your child? Yes No

If yes, please explain.

**#2) Medication Name** \_\_\_\_\_

Dose and Frequency of Medication (e.g. one 250mg tablet two times per day OR 250mg 3 times per day)

When was this medication started? \_\_\_\_\_ Which doctor started this medication? \_\_\_\_\_

Has the medication dosage been changed since the medication was started? Yes No

If yes, how has it changed? Why was it changed?

Why was the medication started? Which symptom(s) or problem(s) is the medication intended to treat?

Has the medication helped these symptoms?

Yes – the symptoms are significantly improved

No – the symptoms are the same

Yes – the symptoms are slightly improved

No – the symptoms are worse than before starting the medication

Please explain your answer above:

Does this medication have any side effects in your child? Yes No

If yes, please explain.

**#3) Medication Name** \_\_\_\_\_

Dose and Frequency of Medication (e.g. one 250mg tablet two times per day OR 250mg 3 times per day)

When was this medication started? \_\_\_\_\_ Which doctor started this medication? \_\_\_\_\_

Has the medication dosage been changed since the medication was started? Yes No

If yes, how has it changed? Why was it changed?

Why was the medication started? Which symptom(s) or problem(s) is the medication intended to treat?

Has the medication helped these symptoms?

Yes – the symptoms are significantly improved

No – the symptoms are the same

Yes – the symptoms are slightly improved

No – the symptoms are worse than before starting the medication

Please explain your answer above:

Does this medication have any side effects in your child? Yes No

If yes, please explain.

**X&Y CHROMOSOME VARIATION MEDICATION PROFILE – PART TWO - PAST MEDICATIONS**

PLEASE FILL OUT THE FOLLOWING ON ALL **PREVIOUS** MEDICATIONS. It is not necessary to fill this out for past antibiotics, etc.

**#1) Medication Name** \_\_\_\_\_

Dose and Frequency of Medication (e.g. one 250mg tablet two times per day OR 250mg 3 times per day)

When was this medication started? \_\_\_\_\_ Which doctor started this medication? \_\_\_\_\_

When was this medication stopped? \_\_\_\_\_

Was the medication dosage been changed during the time the medication was taken? Yes No

If yes, how was it changed? Why was it changed? \_\_\_\_\_

Why was this medication started? Which symptom(s) or problem(s) was the medication intended to treat? \_\_\_\_\_

Did the medication help these symptoms?

- Yes – the symptoms significantly improved
- Yes – the symptoms slightly improved
- No – the symptoms were the same
- No – the symptoms were worse than before starting the medication

Please explain your answer above: \_\_\_\_\_

Why was this medication stopped? \_\_\_\_\_

Did this medication have any side effects in your child? Yes No

If yes, please explain. \_\_\_\_\_

**#2) Medication Name** \_\_\_\_\_

Dose and Frequency of Medication (e.g. one 250mg tablet two times per day OR 250mg 3 times per day)

When was this medication started? \_\_\_\_\_ Which doctor started this medication? \_\_\_\_\_

When was this medication stopped? \_\_\_\_\_

Was the medication dosage been changed during the time the medication was taken? Yes No

If yes, how was it changed? Why was it changed? \_\_\_\_\_

Why was this medication started? Which symptom(s) or problem(s) was the medication intended to treat? \_\_\_\_\_

Did the medication help these symptoms?

- Yes – the symptoms significantly improved
- Yes – the symptoms slightly improved
- No – the symptoms were the same
- No – the symptoms were worse than before starting the medication

Please explain your answer above: \_\_\_\_\_

Why was this medication stopped? \_\_\_\_\_

Did this medication have any side effects in your child? Yes No

If yes, please explain. \_\_\_\_\_