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 5-11 ☐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_____

IN THE SPACE BELOW, PLEASE DISCUSS YOUR PRIMARY CONCERNS AND/OR WHAT YOU PRIMARILY WISH TO TALK ABOUT DURING OUR APPOINTMENT(S) IN OUR CLINIC:

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	☐Amphetamines	☐Methamphetamines
☐Cocaine	☐Alcohol	☐Other (specify)	
☐Heroin	☐Methadone		

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
☐Difficulty sleeping
☐Difficulty feeding
☐Failure to thrive/poor growth & weight gain
☐Colic
☐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?

Has your child ever been hospitalized? ☐Yes ☐No
Has your child ever had surgery? ☐Yes ☐No
If hospitalized and/or surgery, when and why?

Please list all current medications and supplements:

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

☐Birth defect	☐Diabetes	☐Mental Retardation
☐Speech/Language delay	☐High Blood Pressure	☐Learning Disability
☐Chromosomal disorder/genetic syndrome	☐Seizures	☐Depression
☐Autism/PDD	☐Kidney Disease	☐Anxiety Problems
☐Alcohol/Drug Abuse	☐Cancer	☐ADD/ADHD

☐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 WHICH WERE USED TO TREAT BEHAVIORAL, PSYCHOLOGICAL, NEUROLOGICAL, OR OTHER SIMILAR PROBLEMS. 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.