

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

Does your child know his/her diagnosis? Yes No If no, do you plan to tell him/her before this appointment? Yes No

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 Amphetamines Methamphetamines
Cocaine Alcohol Other (specify)
Heroin Methadone

DEVELOPMENTAL HISTORY

- Age when child first rolled over? _____ on time late don't remember
- Age when child first sat alone? _____ on time late don't remember
- Age when child started walking independently? _____ on time late don't remember
- Is your child clumsy/uncoordinated? Yes No
- Can your child use a pencil/crayon? Yes No
- Can your child write his/her name? Yes, at what age? _____ No
- Which hand does your child use for: Writing/drawing? Right Left Eating? Right Left
- Age at child's first single words? _____ on time late don't remember
- What were his/her first words? _____
- Age child spoke in 2 word-phrases? _____ on time late don't remember
- Age child spoke in sentences? _____ on time late don't remember
- Does child have difficulty with pronunciation/enunciation? Yes, what sounds? _____ No
- Can child feed self? Yes, at what age? _____ No
- Can child dress self? Yes, at what age? _____ No
- Can child bathe self? Yes, at what age? _____ No
- Can child help with household chores? Yes, at what age? _____ No
- Does child know home phone number and address? Yes, at what age? _____ No
- Can child tell time accurately? Yes, at what age? _____ No
- Is child toilet trained? Yes, at what age _____ No

BEHAVIORAL/PSYCHOLOGICAL INFORMATION

Does your child currently have, or had in the past, any of the following behaviors on a regular basis. (Check all that apply)

- | | |
|-------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------|
| <input type="checkbox"/> Temper tantrums/Oppositional behavior | <input type="checkbox"/> Bothered by things touching him (tags on his clothing, collars, belts, jewelry etc.) |
| <input type="checkbox"/> Impulsive | <input type="checkbox"/> Motor tics |
| <input type="checkbox"/> Hyperactive | <input type="checkbox"/> Verbal tics |
| <input type="checkbox"/> Short attention span/distractible | <input type="checkbox"/> Resistance to change in routine |
| <input type="checkbox"/> Repetitive Behaviors | <input type="checkbox"/> Cries often |
| <input type="checkbox"/> Perseveration (conversation fixed on specific idea/topics) | <input type="checkbox"/> Anxiety |
| <input type="checkbox"/> Aggressive/destructive behaviors | <input type="checkbox"/> Depression |
| <input type="checkbox"/> Hand flapping | <input type="checkbox"/> Panic Attacks |
| <input type="checkbox"/> Rocking/spinning | <input type="checkbox"/> Reclusive/isolated behavior |
| <input type="checkbox"/> Nailbiting | <input type="checkbox"/> Moodiness/irritability |
| <input type="checkbox"/> Picks/scratches body | <input type="checkbox"/> Hallucinations (visual or auditory) |
| <input type="checkbox"/> Poor coordination | <input type="checkbox"/> Suicidal thoughts |
| <input type="checkbox"/> Bed wetting/soiling | <input type="checkbox"/> Sleep problems/Nightmares |
| <input type="checkbox"/> Daydreaming | <input type="checkbox"/> Masturbates excessively |
| <input type="checkbox"/> Poor eye contact | <input type="checkbox"/> Self injurious (head bangs, bites/hits self) |
| <input type="checkbox"/> Isolated/withdrawn | <input type="checkbox"/> Obscene speech or unfiltered speech |
| <input type="checkbox"/> Overly dependent/immature | <input type="checkbox"/> Fire setting |
| <input type="checkbox"/> Low self-esteem | <input type="checkbox"/> Stealing/Lying |
| <input type="checkbox"/> Shyness | <input type="checkbox"/> Running away |
| <input type="checkbox"/> Excessive worries/fears | <input type="checkbox"/> School refusal/truancy |
| <input type="checkbox"/> Doesn't like to be touched | |

BEHAVIORAL/PSYCHOLOGICAL INFORMATION (continued)

Eating behavior

- Normal Picky, Eats too little Eats too much
Food Cravings? Yes If yes, what foods? No
Problems chewing/swallowing? Yes No
Other eating problems? _____

Social behavior

- Does child make good eye contact? Yes No
Does child like to play with other children? Yes No
Does child have a fear of public places/crowds? Yes No
Does child have poor social skills? Yes No
Does child have friends? Yes No
Does child have frequent conflicts with peers? Yes No
Is child mean to others/bullying? Yes No
Is child a victim of bullying? Yes No
Has child's behavior resulted in problems at school? Yes No
Has child had any problems with the law? Yes No
Does child smoke, use alcohol, illegal drugs? Yes No

PREVIOUS PSYCHOLOGICAL & DEVELOPMENTAL EVALUATIONS

Has your child been previously evaluated for developmental, behavioral, emotional, or learning problems? Yes No

Who performed the previous treatments/evaluations/diagnostic tests? What were the results?

Please include provider name, date performed and results

- Developmental Pediatrician _____
 Neurologist _____
 Psychologist _____
 Psychiatrist _____
 Speech-Language Therapist _____
 Occupational Therapist _____
 Physical Therapist _____
 Mental Health Therapist/Counselor _____
 Other _____

Has your child been previously been diagnosed with? (Please check all that apply)

- Attention Deficit Hyperactivity Disorder (ADHD)
 Autism, Asperger's Syndrome, or Pervasive Developmental Disorder (PDD)
 Learning disability
 Reading disability
 Speech delay
 Mental retardation
 Obsessive-Compulsive Disorder (OCD)
 Depression
 Anxiety Disorder
 Sensory Integration Disorder
 Oppositional Defiant Disorder (ODD)
 Other behavioral, psychologic, or psychiatric disorder?

Has your child ever been hospitalized for psychiatric reasons? No Yes If yes, please explain (when, how long, where, did it help):

MEDICAL PROBLEMS/EVALUATIONS

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

- | | |
|----------------------------------------------|----------------------------------------------------------------------|
| <input type="checkbox"/> Irritability | <input type="checkbox"/> Failure to thrive/poor growth & weight gain |
| <input type="checkbox"/> Difficulty sleeping | <input type="checkbox"/> Colic |
| <input type="checkbox"/> Difficulty feeding | <input type="checkbox"/> Excessive crying |

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)

- | | | |
|----------------------------------------------------------------|----------------------------------------------|----------------------------------------------|
| <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

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. At what age did you first express concern (development, behavior, physical appearance) to your physician?

2. Who first became concerns or suspected a diagnosis of SCA (parents, teachers, physicians, spouse)?

3. What was the first concerning sign or symptom (development, behavior, physical)?

4. If the concerning symptom was developmental delay, at what age did the professional confirm the child had delays?

5. When did the child first receive early intervention therapies?

6. How many times did you visit any doctor or health care professional about your concerns before chromosomal testing was ordered?

7. Who first recommended a chromosome test (parents, teachers, friend, endocrinologist)?

8. At what age was a chromosome test ordered? _____

9. At what age did you receive the SCA diagnosis? _____

10. Who made the diagnosis? (geneticist, endocrinologist, developmental pediatrician) _____

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.

#4) 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.

#5) 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.

#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? _____

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.

#4) 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.
