

GENERAL INFORMATION

Today's Date: _____

Your 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) do you have? _____

You were diagnosed: Prenatally before age 5 age 5-11 age 12-18 after age 18

When did you learn your diagnosis? _____ Who told you? _____

Approx. weight ? _____ Approx. Height? _____

CURRENT FAMILY SITUATION

Mother's Name: _____ Age: _____ Education: _____

Relationship to you : 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 her? Yes No

Father's Name: _____ Age: _____ Education: _____

Relationship to you : 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 him? Yes No

With which parent(s) do you the live? Both Mother Father Neither Other

If Parents are separated or divorced, what year did this happen? _____

Do any other adults live in your home? Yes No If yes, Name, Age, Relationship: _____

Doctor's Name _____ Phone _____

Address: _____ City _____ State _____ Zip _____

BIRTH INFORMATION

Birth weight? _____ Type of Delivery? Vaginal Cesarean Twins

Describe any complications during delivery or in the hospital if known: _____

PREGNANCY INFORMATION

Mother's age during this pregnancy? _____ Father's age during this pregnancy? _____

Did your 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?)

BEHAVIORAL/PSYCHOLOGICAL INFORMATION

Do you 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 | |

Social behavior

- | | | |
|---|------------------------------|-----------------------------|
| Do you make good eye contact? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Do you have friends? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Do you have a fear of public places/crowds? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Do you have poor social skills? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Do you have frequent conflicts with peers? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Are you mean to others/bullying? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Are you a victim of bullying? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Have you behavior resulted in problems at school? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Have you had any problems with the law? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| Do you smoke, use alcohol, illegal drugs? | <input type="checkbox"/> Yes | <input type="checkbox"/> No |

PREVIOUS PSYCHOLOGICAL & DEVELOPMENTAL EVALUATIONS

Have you 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 _____

Have you 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?

Have you ever been hospitalized for psychiatric reasons? No Yes

If yes, please explain (when, how long, where, did it help):

EDUCATIONAL HISTORY

Did you attend:

<input type="checkbox"/> Elementary/Middle school?	If yes, until what age? _____	<input type="checkbox"/> Private	<input type="checkbox"/> Public	Completed Grade Level _____
<input type="checkbox"/> High school?	If yes, until what age? _____	<input type="checkbox"/> Private	<input type="checkbox"/> Public	Completed Grade Level _____
<input type="checkbox"/> College?	If yes, until what age? _____	<input type="checkbox"/> Private	<input type="checkbox"/> Public	Completed Grade Level _____

Have you ever repeated a grade? Yes. What grade? _____ No

School Assessments and Intervention

Did you have special education testing in school?

- Psychological/Cognitive Date: _____
- Academic Date: _____
- Speech/Language Date: _____
- Other Date: _____

Did you have an IEP? Yes, when? _____ No

Special Education Classes/Services: Please check all that apply (Specify what grade/frequency/duration)

- Special Education
- Learning Disability
- Speech/Language Therapy
- Occupation/Physical therapy
- Behaviorally/emotionally handicapped
- Other health impaired
- Other

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

MEDICAL PROBLEMS/EVALUATIONS

Do you 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) _____
Have you 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 you? _____

Have you ever been hospitalized? Yes No
Have you 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?
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

FAMILY MEDICAL HISTORY

Mother: Health, learning, mental health problems? Yes No If yes, please describe: _____

Medications she is 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 he is 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: _____

Your birth date: _____

Your current age: _____

Which type of SCA Do you have? (47,XXY; 47,XXX; 47,XYY, etc): _____

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

2. Who first became concerned 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 you had delays?

a. When did you first receive early intervention therapies?

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

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

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

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

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

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

PLEASE LIST THE MEDICATIONS YOU ARE 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 you? 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 you? 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 you? 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 you? 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 you? 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 you? 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 you? 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 you? 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 you? Yes No

If yes, please explain.