

Legal Issues and Challenges

AXYS

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CAVEATS

- AXYS is a non-profit 501(c)(3) organization that provides advocacy, education and support for individuals with X and Y chromosomal variations (“X/Y”) and their families.
- Focus is on 47,XXY/KS, but any individual with an X /Y chromosomal variation may experience similar issues. All X/Y individuals are unique and this presentation is not intended to imply that all X/Y persons will have or encounter the matters covered.
- AXYS is not a law firm and does not provide legal advice.

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OBJECTIVES

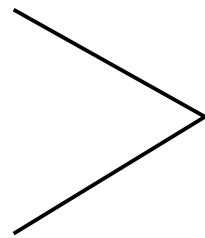
1. General overview of U.S. criminal justice system, including information relevant to X/Y individuals.
2. Your role in the process.
3. Understanding impact/role of X/Y chromosomal variations.
4. Support, medical, legal and other resources available.

U.S. CRIMINAL JUSTICE SYSTEM

Federal Crimes

State Crimes

Local Crimes



Felony or Misdemeanor

- Usually, State statutes will specifically classify a crime as a felony or a misdemeanor based upon the facts alleged, with felonies being more serious offenses.
- Both generally carry the possibility of jail time; a misdemeanor is, generally, a crime that is a “lesser” criminal offense and, in Ohio, incurs not more than 1 year of jail time (in a local jail) and fines up to \$1,000.

U.S. CRIMINAL JUSTICE SYSTEM (CONTINUED)

- Examples of misdemeanors (Ohio – 5 levels, with 1st degree being most serious):
 - * Petty theft
 - * Trespassing
 - * Disorderly conduct
 - * Speeding
 - * DUI
 - * Public fighting
 - * Battery
 - * Possession of drug paraphernalia
- With misdemeanors, judge usually has the ability to impose alternative or additional penalties:
 - * Probation
 - * House arrest with monitoring
 - * Parole
 - * Weekend imprisonment
 - * Community service
 - * Counseling/treatment
- Your criminal record is public and potential employers can access it:
 - * Federal and State laws and regulations govern potential employer's ability to use criminal record in denying employment.
 - * Expungement of a State misdemeanor conviction can (generally) be done (also some felonies), but isn't an easy process with a certain outcome. Must present compelling evidence to the judge after a certain period of time with no intervening convictions. After expungement, you can honestly answer that you have never been convicted of a crime (the expunged crime only).

U.S. CRIMINAL JUSTICE SYSTEM (CONTINUED)

- Examples of felonies (Ohio – 5 levels, with 1st degree being most serious; incarceration from 1 year to life and fines from \$2,500 to \$25,000):
 - Examples of Ohio felonies with mandatory prison terms:
 - * Possession of a firearm during a felony
 - * Kidnapping
 - * Voluntary manslaughter
 - * Rape or attempted rape of a child under 13
 - * Grand theft of a motor vehicle
 - * Unlawful sexual contact with a minor
 - * Breaking and entering
 - * Gambling
 - * Vehicular assault
 - * Illegally manufacturing or processing explosives

FEDERAL MISDEMEANORS AND FELONIES

- Classified from Class A felonies – Class E felonies with penalties ranging from life imprisonment or death / \$250,000 maximum fine to Class A misdemeanors – Class C misdemeanors with penalties ranging from 1 year or less but more than 6 months / \$100,000 maximum fine to 30 days or less but more than 5 days / \$5,000 maximum fine.
- “Infraction” – no classification; 5 days or less prison term and maximum \$5,000 fine.
- Federal Sentencing Guidelines sets out an advisory (not mandatory) uniform sentencing policy for persons convicted of a felony or a serious (Class A) misdemeanor.

FEDERAL MISDEMEANORS AND FELONIES (CONTINUED)

- Federal Juvenile Delinquency Act (18 U.S.C. §§5031-5042).
- Expungement of conviction not normally available.
- Federal felony examples (on Federal property):
 - * Possession of a firearm during a felony
 - * Aggravated assault
 - * Obstructing or impeding officers
 - * Drug trafficking
 - * Drug manufacturing

FEDERAL MISDEMEANORS AND FELONIES (CONTINUED)

- Federal misdemeanor examples:
 - * Assaults within maritime or territorial jurisdictions (i.e., a National Park)
 - * Civil rights misdemeanors
 - * False claims for postal losses
 - * Counterfeiting / forging (dollar limits)
 - * Desecration of U.S. flag
 - * False use of name to indicate Federal agency
 - * Transporting fireworks into a State prohibiting use or sale
 - * Storage of explosive materials
 - * Mailing threatening communications
 - * Possession of firearms and dangerous weapons in a federal facility (i.e., NIH)
 - * Certain ID fraud
 - * Certain computer fraud
 - * Cutting / injuring trees on Federal land
 - * Violations of National Park regulations

YOUR RIGHT TO REMAIN SILENT

- Other than as discussed later, you do not have to answer any questions from the police. But, not a simple answer.
- *Miranda v. Arizona*, 384 U.S. 436 (1966) (5-4 decision)
 - Significant U.S. Supreme Court case that ruled a defendant's statements to authorities are inadmissible in court unless the defendant has been clearly informed of his legal rights prior to interrogation:
 - You have the right to remain silent.
 - Anything you say can and will be used against you in court.
 - You have the right to consult with a lawyer and, if you invoke this right, the interrogation must stop until the attorney is present.
 - You have the right to have the lawyer with you during questioning.
 - If you/the defendant is indigent, a lawyer will be appointed to represent you.
 - You can invoke your right to remain silent before or during an interrogation and, if you do invoke your right, the interrogation must stop.

YOUR RIGHT TO REMAIN SILENT (CONTINUED)

- States have their own variations of the language used.
- Key addition (not universal in all States) has been to include at the end a question along the lines of: “Do you understand these rights as they have been read to you?”
- *Miranda* warnings not required unless:
 - You are in police custody and
 - You are under interrogation by the police.
- “Police custody” – any time the police deprive you of your freedom of action in any significant way.
 - Realistically means when you have been arrested.
- “Interrogation”
 - A request for identification is generally not considered an interrogation.
 - Once police officers begin asking questions that may implicate your involvement in a crime, interrogation has begun.

YOUR RIGHT TO REMAIN SILENT (continued)

- **YOU MUST AFFIRMATIVELY INVOKE YOUR RIGHT TO REMAIN SILENT.**

- Fifth Amendment to the U.S. Constitution: “[n]o person...shall be compelled in any criminal case to be a witness against himself.”
- Not sufficient if you just remain silent or refuse to sign an acknowledgment you have been given your *Miranda* rights.

YOUR RIGHT TO REMAIN SILENT (continued)

- **WHAT TO SAY:**
 - **“I WANT A LAWYER.”**
 - **“I WANT TO REMAIN SILENT.”**
 - **“I DON’T UNDERSTAND AND I WANT A LAWYER NOW.”**
 - *Maryland v. Shatzer*, 559 U.S. 98 (2010). Defendant invoked his right to remain silent during a police interview (after he had waived his *Miranda* rights) and the interrogation stopped and he was placed back with the general prison population. Almost 3 years later, investigation was reopened and Shatzer waived his *Miranda* rights in writing twice and after he failed a polygraph test, he was questioned more and confessed and then requested an attorney. He was convicted of child sexual abuse. Supreme Court held his statements were admissible because there had been a “break in custody” of at least 14 days (i.e., almost 3 years) during which time he was freed from the residual coercive effects of his prior custody. The “14-day break in *Miranda* custody” rule.

YOUR RIGHTS IF YOU ARE STOPPED OR QUESTIONED

- Police have the power to approach a person and ask them questions (“Hey, what are you doing here?”).
- With 1 exception, you have no legal duty to answer questions.
 - You do have to identify yourself: name, address and birthdate. Failure to do so is a 4th degree misdemeanor (Ohio law) and you can be arrested.
 - If in a motor vehicle, you must show your driver’s license, registration and proof of insurance.

WHAT TO DO IF YOU ARE STOPPED OR QUESTIONED

- ALWAYS:
 - KEEP YOUR HANDS WHERE THE POLICE CAN SEE THEM
 - BE POLITE AND RESPECTFUL.
 - STAY CALM AND IN CONTROL OF YOUR EMOTIONS, WORDS AND BODY LANGUAGE.
 - REMEMBER ALL OF THE OFFICERS' BADGES AND PATROL CAR NUMBERS.
 - WRITE DOWN EVERYTHING YOU REMEMBER AFTER THE INCIDENT.
 - TRY TO LOCATE WITNESSES AND GET THEIR CONTACT INFO.
 - TAKE PICTURES OF ANY INJURIES (DATE STAMP).

WHAT TO DO IF YOU ARE STOPPED OR QUESTIONED (CONTINUED)

- SHOULD:
 - YOU INVOKE YOUR RIGHT TO REMAIN SILENT?
- NEVER:
 - RUN AWAY OR TRY TO LEAVE THE SCENE.
 - ARGUE WITH THE OFFICERS.
 - RAISE YOUR VOICE, SWEAR OR CALL THE OFFICERS A DISPARAGING NAME.
 - RESIST THE OFFICER EVEN IF YOU KNOW YOU ARE INNOCENT.
 - LIE (CRIME: OBSTRUCTING OFFICIAL BUSINESS).

WHAT TO DO IF YOU ARE STOPPED OR QUESTIONED (CONTINUED)

- A person is “stopped” or “detained” when an officer uses enough force, or a “show of authority” to make a “reasonable person” feel he is not free to leave.
 - “Stop. I want to ask you a question.”
- ALWAYS, SHOULD AND NEVER ALL APPLY
- Officer should have a reasonable suspicion that you have been involved in a crime before he interferes with your liberty to move about. If later end up in court, prosecutor must prove the basis of the reasonable suspicion. Officer does not have to tell you that you are a suspect or that he intends to arrest you.

WHAT TO DO IF YOU ARE STOPPED OR QUESTIONED (CONTINUED)

- Same rights apply and you also have the right to refuse to give consent to a search of your person, vehicle or home.
 - But, the law does allow a limited search (such as a “pat down” or shining a light into a vehicle) to search for weapons.
- If officer says he has a warrant (a legal document issued by a judge or clerk of courts directing police to arrest you and take you into custody) he is not required to show it to you.
 - Police must show you the warrant within a reasonable time after arrest and give you a copy.
- Once the officer has no grounds to detain you, he should say you are free to go. If he doesn't, ask: “Am I free to go.” If he says not yet, ALWAYS, SHOULD AND NEVER still apply.

WHAT TO DO IF YOU ARE STOPPED OR QUESTIONED (CONTINUED)

- Officer must see the crime or have “probable cause” to believe you committed a crime. Don’t argue with the officer; prosecutor will need to prove probable cause in court.
- You can be taken into custody to determine your identification.
 - You are now in custody and your *Miranda* rights arise once he/another officer begin to ask you questions.
 - You have no right to argue or resist.
 - ALWAYS, SHOULD AND NEVER ALL APPLY.
 - ALWAYS ASK FOR A LAWYER AND THEN, NO MATTER HOW UNCOMFORTABLE IT IS, BE SILENT.

WHAT TO EXPECT AND WHAT NOT TO EXPECT

- Steps:
 1. Arrest.
 2. Booking.
 3. Detention (until court hearing or you make bail).
 4. Meet with your lawyer.
 - It is important you come to the meetings prepared. Some criminal defense attorneys will ask you to fill out a questionnaire before your meeting. Also, forward or bring any documents the lawyer has requested.
 - You should also bring several items that will help the lawyer assess your case, including:
 - Any documents you received from the court showing your charges and next court appearance date.
 - Your bail papers.
 - If your property was searched, any paperwork the police gave you.
 - A copy of the police report if possible.
 - A list of any witnesses, victims and other defendants. They need to verify that neither they nor anyone else in their office has ever represented any of the other parties. If one has, then that lawyer may not be able to represent you because of a *conflict of interest*.

WHAT TO EXPECT AND WHAT NOT TO EXPECT (CONTINUED)

4. Meet with your lawyer (continued).
 - You should also bring a list of questions to ask in an effort to decide whether to hire the lawyer.
 - Where did you attend law school? When did you graduate?
 - How long have you been practicing criminal law?
 - How often do you appear in the courthouse where my case will be handled?
 - Do you frequently negotiate plea agreements with the prosecutors office? How would you describe your relationship with the prosecutor's office?
 - How often do your clients go to trial?
 - How familiar are you with the charges against me? What percentage of your practice is in representing clients with similar charges?
 - Do you belong to any bar associations or other professional organizations? If so, which ones?
 - What are my legal options? Would you recommend a guilty plea, a plea agreement, or a trial?

WHAT TO EXPECT AND WHAT NOT TO EXPECT (CONTINUED)

4. Meet with your lawyer (continued).

- What aspects of my case work in my favor?
- What potential problems do you foresee with my case?
- What can I expect at the different stages of the process, including arraignment, filing of motions, motions hearing, disposition, and trial?
- Are you available to represent me?
- Will anyone else work on my case? May I meet them?
- Will you be personally representing me in court, or will that responsibility go to someone else? If so, who?
- If I have any questions, do I call you? Or someone else? If so, who?
- How do you and your colleagues prefer to be contacted? How quickly can I expect a response?
- Do you charge an hourly rate or a flat fee?
- If you charge by the hour, what is your rate? Will I have to pay a retainer fee? How will that work?
- If you charge a flat fee, what is it? What does it include? What doesn't it include? Is it refundable? Do I have to pay it all up front?
- What other expenses would I have to pay outside of your fee? Can you give me an estimate for them?

WHAT TO EXPECT AND WHAT NOT TO EXPECT (CONTINUED)

5. Arraignment – 1st court appearance
 - Judge will appoint a lawyer if you are “indigent.”
 - Enter a plea of not guilty, guilty or no contest.
 - If you enter a plea of guilty or no contest, judge can sentence you directly or set a later date for sentencing.
6. Preliminary hearing.
 - Prosecution must demonstrate to the judge that there is enough evidence against you to establish “probable cause” that you committed the crime with which you are charged.
 - Your lawyer can cross-examine prosecution’s witnesses in the case.
 - You can never be compelled to take the stand and testify.

WHAT TO EXPECT AND WHAT NOT TO EXPECT (CONTINUED)

7. Hearing before judge to suppress evidence.
 - Inadmissible statements (*Miranda* violation)
 - Unreasonable search (without a warrant, your consent or in emergency circumstances)
 - Illegal traffic stop (police pulled you over without a reasonable suspicion you were doing something illegal).
8. Plea bargain.
 - A negotiated agreement to reduce charges to a lesser crime to increase your chances of receiving a lesser sentence.
 - Judge is not bound to honor the plea agreement.
9. Trial.
10. Sentencing.
11. Appeal.

WHAT TO EXPECT AND WHAT NOT TO EXPECT (CONTINUED)

- WHAT CAN YOU DO?
 - Not all lawyers, judges, police are created equal.
 - Lawyers are not miracle workers.
 - Stick to the facts.
 - The law is often unfair.
 - Unless it is a serious case, you are a number in a process and the process is long, uncertain, confusing and exhausting.
 - Dress appropriately for court – your family and friends also.
 - Suit or sport coat and slacks.
 - Wear a tie.
 - No sneakers or sandals or inappropriate boots, etc.
 - Personal grooming.
 - Remove piercings, no gum chewing, eating or drinking.
 - Be polite and respectful: “Your honor,” “sir,” “Ma'am.”
 - Never, ever miss or be late for a court date. Call the Clerk of Courts for date, time and location if your lawyer isn’t being responsive. Court can issue a warrant for your arrest if you don’t show up.

WHAT TO EXPECT AND WHAT NOT TO EXPECT (CONTINUED)

- TURN OFF AND PUT AWAY ALL CELL PHONES. NO EXCEPTIONS.
- Leave children at home.
- LET YOUR LAWYER DO THE TALKING.
 - Answer only when the judge speaks directly to you and answer only the question asked. Never volunteer anything. If you don't understand, quietly ask your lawyer to explain it to you. You can take a break to consult with your lawyer.
- Do not engage in a stare-down or any other behavior that could be interpreted as hostile or disrespectful.
- Stand up straight – don't slouch – keep your hands out of your pockets.
- Discuss exact terms of your bail, plea deal and sentence with your lawyer until you know all exact information.
- NEVER talk about your case with anyone but your lawyer and NEVER in a public place. Privilege/waiver issues.

WHAT TO DO AS A PARENT

- You are the most important advocate for your child.
- Practice role playing with your son.
 - Questioning
 - Stopped
 - Custody
- How to invoke your right to remain silent.
- How to not give your consent to a search.
- How to ask for your lawyer.
- How to say: “I have a disability and I don’t understand. I want a lawyer.”
- What does your budget allow?
- Guardianship of the person and estate.
- Does your community have a “Sequential Intercept Model” or similar program to prevent individuals with mental illnesses from entering/going deeper into the criminal justice system? (Dr. Mark Munetz)
- Your cellmate is not your friend.

WHAT TO DO AS A PARENT (CONTINUED)

- Your son is entitled to receive all medications and has a right to treatment while detained/in jail. Your lawyer should handle all arrangements. If you don't have a lawyer yet, you should call the jail directly and get things rolling re: medication.
- You have to take an active role in educating your lawyer and your lawyer should be willing and able to present any X/Y variation matters that may be helpful. You should give lawyer a copy of the diagnosis, all brain imaging studies, neuropsychological, auditory and any other tests that may be relevant.
- You should give the lawyer the AXYS website (www.genetic.org) and phone number (1-888-999-9428).
- You should print off 2 copies of all medical research that supports your claims and take them to your lawyer. (AXYS, PubMed)
- AXYS White Paper (Criminal Justice Task Force). The following slides discuss impact of the condition addressed in the white Paper with citations to peer-reviewed medical articles and other resources.
- Experts; mental health attorney.
- Research available alternative sentencing and treatment. If crime is drug-related, or your son has substance abuse issues, don't ignore them. Best to start treatment before your 1st or 2nd court appearance. Keep records.

IMPACT / ROLE OF X/Y CHROMOSOMAL VARIATIONS

- Testosterone therapy is not a cure for neurodevelopmental effects of 47,XXY/KS.
- While there is absolutely no proof that a male diagnosed with 47,XXY/KS, or any person diagnosed with any other X / Y chromosome variation, is predisposed to criminal activity or behavior, certain neuropsychological and behavioral implications of the conditions are important considerations for those individuals who do find themselves involved in the criminal justice system. The variability of the neuropsychological and behavioral features associated with 47,XXY/KS and other X/Y variations is significant.
- Impaired cognitive abilities: Cognitive abilities are the underlying brain-based skills that we need to carry out any task, from the simplest to the most complex. Cognitive abilities allow us to think, learn and remember.
- Significant frontal-executive functioning deficits, such as issues with judgment, problem solving, decision making, memory, emotional self-regulation, concept formation, switching tasks, mental flexibility, problems with inhibitory skills (a prevalent issue), attention deficit disorder, impulse control disorder, short attention span, distractibility and poor organization.

IMPACT / ROLE OF X/Y CHROMOSOMAL VARIATIONS (CONTINUED)

- Pervasive learning disabilities; verbal abilities and related language-based or reading deficits, such as dyslexia, verbal fluency, word retrieval, auditory processing and verbal memory, language comprehension and expression, and attentional deficits. These deficits cause children to fall behind in subjects where instruction is largely verbal based so that the late adolescent 47,XXY/KS males can be several grade levels below their peers.
- Autism spectrum disorders and psychotic symptoms including paranoia, schizophrenia, delusional thinking and hallucinations; behavioral issues such as shyness, irritability, meltdowns, social withdrawal, depression, anxiety. Overall, depression, anxiety and other psychiatric disorders are strikingly higher in males with 47,XXY/KS than in the general population. These behavioral issues are also found in several other developmental disorders, such as autism.
- These deficits persist into adulthood. There has also been recent research that shows the brain areas that process emotional interpretation in some 47,XXY/KS individuals have a different anatomical structure than the norm. This could be the reason that some 47,XXY/KS individuals have difficulty interpreting social cues and may react, or appear to be under-reacting, to emotional situations. With speech and language challenges (again, associated with their neuroanatomy) they may also have difficulty verbalizing their feelings. This can often be misinterpreted by people not familiar with the condition (including police, prosecutors, judges, psychologists, etc.) as the person not being concerned or remorseful because their physical appearance remains unexpressive and they are not able to articulate how they feel.

IMPACT / ROLE OF X/Y CHROMOSOMAL VARIATIONS (CONTINUED)

- While the picture of 47,XXY/KS neuroanatomy is complex, magnetic resonance imaging and neuroimaging studies have found significant structural brain differences in males with 47,XXY/KS that are consistent with the characteristic, but highly variable, intellectual and behavioral features of males with 47,XXY/KS. These studies have shown smaller total cerebral volume (consistent with smaller head size) and all lobular volumes (other than parietal white matter). These structural brain differences are consistent with the cognitive/behavioral phenotypes reported for 47,XXY/KS males:
 - Significant frontal-executive functioning deficits, including problems with judgment, decision making and poor inhibitory control (thought to be related to smaller frontal and caudate volumes).
 - Impairment of planning and integration of motor movements, muscular weakness in the upper trunk and shoulders (thought to be related to the thinning of the motor cortex and the smaller frontal and caudate volumes).
 - Language processing, reading, developmental and learning disabilities (thought to be related to cortical thinning in the superior region of the motor strip and abnormalities of the caudate nucleus).
 - Mood and emotional modulation (thought to be related to reduced volumes in the insula, hippocampus and medial limbic system (associated with mood and emotional modulation).

IMPACT / ROLE OF X/Y CHROMOSOMAL VARIATIONS (CONTINUED)

- While 47,XXY/KS is not a prima facie defense in any case, we do believe that it can be substantially mitigating factor in an individual's defense or sentencing. A number of factors can contribute to poor judgment and impulsive behaviors that can contribute to criminal behavior:
 - Executive function problems frequently manifest as impulse control problems, poor judgment and inappropriate emotional outbursts. None of these things typically lead to serious misbehaviors, but when provoked by others or tempted by opportunities, 47,XXY/KS individuals may make poor choices. Immaturity may lead a young adult to behave more like a rebellious adolescent. And when faced with an authority figure, for example a police officer, they may have an outburst or "meltdown" rather than recognize the risk of the situation and behave accordingly.
 - Delayed social development: many of those who are 47,XXY/KS experience social delays that can put them at risk—especially in the critical years transitioning from adolescence to adulthood. It is not uncommon for young adults who are 47,XXY/KS to persist in juvenile behaviors, such as Yu-Gi-Oh!, Anime, and so on. They may seek out social peers who are 5 to 10 years younger than they are. Many have a natural attraction to girls who are significantly younger simply because these girls are their social peers.
 - Failure to learn from prior adverse experiences or outcomes.

IMPACT / ROLE OF X/Y CHROMOSOMAL VARIATIONS (CONTINUED)

- Communication deficits are prevalent. A recent study in the Netherlands showed that many 47,XXY/KS individuals struggle to interpret facial expressions. For example, they struggle to distinguish between anger and sadness. This inability to pick up on the nuance of communication puts them at a significant disadvantage in challenging social situations. They can be emotionally isolated and unable to empathize with others, because they don't fully grasp the other person's point of view.
- Bullying by others is prevalent. This abuse puts them on the defensive, and it often injects them into the spotlight when they respond to bullies. As seen above, being the focus of what they perceive as unjust attention from authorities may provoke inappropriate behaviors. Also, in an effort to seek refuge from or please a bully to get the bullying to stop, 47,XXY/KS individuals may impulsively seek out support from others who may be able to fend off the bullies. In some cases, these so-called friends may further exploit or abuse the 47,XXY/KS individual.

IMPACT / ROLE OF X/Y CHROMOSOMAL VARIATIONS (CONTINUED)

- Social behavior and social cognition: Ongoing research into the relationship between brain structure and function and areas involved with social behavior is helping us understand why some 47,XXY/KS individuals can struggle with perception, reasoning, attention and decision-making while appearing to have normal intellectual functioning. Many 47,XXY/KS individuals have characteristics and behaviors that will place them on the autism spectrum disorder spectrum (ASD) where general intellectual functioning can be disassociated from social behavior and social function in very dramatic ways. In particular, impulsive behavior has been shown to be associated with a decoupling of prefrontal and subcortical networks which has been demonstrated in a number of 47,XXY/KS research studies. In more simple terms, some 47,XXY/KS individuals can appear to be intelligent, capable, goal-directed and responsible but at the same time have significant challenges with consistent decision-making and impulsivity that is related to impaired neurobiological development.
- Age-appropriate sexual interactions. This seems to be a particularly difficult area for many reasons. The mismatch between chronological age and actual maturational age; the difficulty with communication and emotional intelligence; the perception they are responsible, functional adults; executive decision-making deficits; fluctuations in testosterone levels if receiving hormone replacement therapy; learning challenges and more. If there is one area that makes some 47,XXY/KS individuals highly at risk for inappropriate behavior and subsequent severe legal punishments, it would be this area. They have been dealt a genetic hand that is the equivalent of a perfect storm of potential disaster.

IMPACT / ROLE OF X/Y CHROMOSOMAL VARIATIONS (CONTINUED)

- In summary, the following issues should be considered with an 47,XXY/KS individual that may be experiencing difficulty that involves the criminal justice system:
 - 47,XXY/KS is a genetic condition that can have numerous medical, social, emotional, psychological and behavioral implications.
 - Outside of a small number of trained and experienced health professionals, it is a condition that is not well-understood by the general medical community.
 - 47,XXY/KS individuals, especially adults, should be considered a vulnerable population that may need special support and advocacy when involved with the criminal justice system. Parents and other family members may not always be aware of or understand the need for special advocacy.
 - Treatment and special support are more appropriate responses than punitive consequences for 47,XXY/KS individuals needing help with managing behavior.

RESEARCH, RESOURCES AND TREATMENT

- AXYS Goal – All families impacted by any of the chromosomal variations have access to the best possible evaluation and treatment.
- The National Institutes of Health in Bethesda, Maryland is engaged in ongoing research regarding X/Y chromosome variations in children, adolescents and adults. Dr. Nicole Banks @ Nicole.banks@NIH.gov; Office of Patient Recruitment (1-800-411-1222 (adult) Study 12-HG-0181.
- As part of its efforts to promote research, AXYS provides the XXYON Registry which helps individuals with X/Y chromosome variations and clinical researchers find each other.
- AXYS also serves an important function to the medical community as a source of information and through its AXYS Clinic and Research Consortium (ACRC). ACRC is a clinical consortium that assists independent multidisciplinary and single specialty clinics committed to X/Y genetic conditions in collaborating with one another, sharing informational resources, and exploring opportunities to participate in joint research projects. AXYS organizes annual meetings of the consortium at which members meet to discuss research and issues important to the X/Y chromosome variation community.
 - Members of the ACRC in 2017 include:
 - Children's Hospital Colorado: eXtraordinary Kids Clinic (www.childrenscolorado.org) (Dr. Nicole Tantaglia)
 - Johns Hopkins: 47,XXY Klinefelter Syndrome Clinic
 - Stanford University School of Medicine
 - Nemours Alfred I. DuPont Hospital for Children: eXtraordinary Kids Clinic
 - Cedars Sinai, Los Angeles
 - Emory University, The eXtraordinaryY Clinic at Emory
 - Rush University Medical Center, Chicago
- For further information, including clinics which are members of ACRC and research and clinical trials, please visit the AXYS website at www.genetic.org or call 1-888-999-9428.
- Neuropsychological exam.
- Local Legal Aid Society.

AXYS Assistance

- Non-legal
- Professional Advisory Committee
- AXYS Criminal Justice Task Force White Paper (citations to peer-reviewed publications)
- Online Library