

### When Others Don't Get It



Looking to the Future  
For X and Y Chromosome Variations  
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**Sharron Close PhD, MS, CPNP-PC**  
**Yale School of Nursing**

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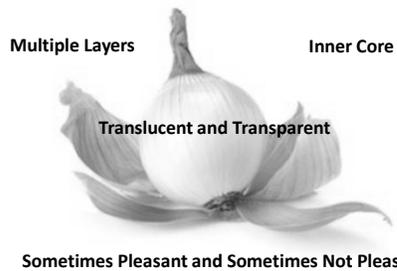
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### Perceptions and Peeling of Onions



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### Identifying Problems

- What Don't They Get?
- Who Doesn't Get It?
- What Do They Need to Get It?
- What Do You Need to Be Satisfied that They Got It?

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### **How to Deal with Educators**

- “Schools lack of understanding around how KS effects our boys.”
- “I am often banging my head against a brick wall. As my son is approaching high school it scares me he wont get the support he needs.”
- “Neurobiological development and treatments.”
- “Educational and classroom techniques and supports.”

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### **What Bothers You?**

- “That misconception that because 75% of those with KS are undiagnosed that MY child's 'issues' are not KS related.”
- “The need for a karyotype before any diagnosis of ASD, ADHD or psychological disorder is given.”
- “The correlation between KS and ASD.”

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### **Communication & Knowledge Transfer**

- “The misconception that our boys are lazy, undisciplined, willful etc. When in fact they have a learning disability, sensory integration difficulties and difficulty with language processing.”
- “Also add in just because our boys may ‘perceive’ things differently, doesn't make it wrong, and teachers/people need to realize this”

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### Dismissal of Concern & Lack of Knowledge by HCPs

- “What bothers me is when your doctor tells you there’s nothing wrong with you”
- “A more in depth medical knowledge by Dr’s and in particular Endocrinologists of the ‘holistic’ effect of low testosterone.”
- “I think the biggest problem is for health practitioners. My GP found little but what was on WebMD and Wikipedia, plus a few other articles in a reference book about KS. My therapist also was stymied by the lack of clinical studies.”

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### Poor & Hurtful Discipline in School

- “Yeh when I was at school, I was put out of most of the class rooms because I was sleepy and destructive, so they put me out in the main corridor, with a table and chair to my self...”
- **EXCLUSION** and **ISOLATION** is a common tactic still used in our schools.
- These methods **lower self-esteem, increase anxiety & frustration, provoke bullying** and do little to address the learning and/or behavioral needs of the child.

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### What Needs to Happen

- A request as simple as providing the child with written directions whom has auditory memory or processing difficulties is ignored let alone anything more complex or in depth that WILL set the child up for success.
- The reason we are given as parents for this is; not enough MONEY to provide extra RESOURCES (classroom support persons).
- Sadly, teachers are not educated on how our kids learn and the bottom line is the bottom dollar

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**Poor Outcomes Visited Upon the Child**

- “Teachers are unable to **MANAGE** or **DIRECT** the child's attention and **SUPPORT** or **ACCOMMODATE** their learning needs.
- In my opinion, it is clearly **VICTIMIZATION** and **DISCRIMINATION** of a child with a **DISABILITY**.
- The child is **BLAMED** for their difficulties and too often too little is being done in schools to **TEACH** the child the specific social skills, coping skills and learning strategies they need to remain in an **INCLUSIVE** learning environment. “

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What Needs to Happen Next?



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