

# Disclosing a DSD: My Story

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# Objectives

- Appreciate the patient and parent perspectives with respect to the disclosure process
- Develop a framework for creating and carrying out a disclosure plan with the family of a child with a DSD

# A (Brief) Timeline

- 1990: Inguinal hernia leads to dx of AIS
- 2000: Mom finds and joins AISSG-USA
- 2002: Full disclosure of syndrome name and karyotype
- 2003: First AISSG meeting
- 2006: Forays into advocacy
- 2007: Appearance on Oprah Winfrey Show “Growing up Intersex”

# My Disclosure: The Good

- Process-oriented
  - Childhood, adolescence, young adulthood
- Age-appropriate language
  - “This is where a baby grows”
- Enlistment of help
  - Medical and psychosocial
- Reinforcement of unrelated strengths
  - Music, leadership, school

# My Disclosure: The Not Good

- Exclusion from conversations with MDs
  - Talking over and around, especially early on
- Failure to follow up
  - Reluctance to ask questions
- Full disclosure as an event
  - Hierarchy of information
  - Age-appropriate knowledge

# Preparing for disclosure

- Start the conversation early
- Recruit help
  - Support groups, support groups, support groups!!
  - Healthcare team
- Gather information
  - Create a binder of resources, letters, movies
  - [www.AccordAlliance.org](http://www.AccordAlliance.org)

# Working towards full disclosure

- Follow up with the child regularly
  - “Tell me what you know about...”
- Time with interventions
  - Understand need for HRT or surgery
- Avoid a hierarchy of information
  - Infertility not always less traumatic than karyotype

# After full disclosure

- Sustain the conversation
  - Continue to ask and answer questions!
- Encourage child to take ownership
  - Teen groups
- Continue to make resources available
  - Psychosocial support for both parents and child
- Reinforce identity outside of DSD
  - Develop tools for discussing with friends and family



# In Conclusion: Remember your ABCs

- A: Ask Questions
- B: Babies Bounce!
- C: Call for Help
- D: Develop Identity outside of DSD
- E: Evolve
  
- S: SUPPORT GROUPS!!!