

## Medical Care for Intersex A Patient-Centered Approach

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Intersex Society of North America  
[www.isna.org](http://www.isna.org)

## Who is the Intersex Society (ISNA)?

- n Founded 1993
- n IRS 501c3 tax exempt status
- n Communication with:
  - 100s of adult intersex people worldwide
  - dozens of parents
- n members (donors)
  - over 250 paying members (donors)
  - 25 members are MDs

## Three Misconceptions about the Intersex Society

- n ISNA does not advocate a “third sex”
- n ISNA is not “anti-surgery”
- n ISNA does not advocate “do nothing”

## An end to shame, secrecy, and unwanted surgery

## Old Model: Surgery-centered (Sexual ambiguity is shameful)

- n parents can't tolerate ambiguity
  - rapid resolution necessary
- n child must be protected from awareness of own ambiguity
  - early surgery

## Invalid Assumptions I

- n painful information is easier if kept secret or misrepresented
- n surgery produces normal looking genitals
- n surgery doesn't damage sexual sensation
  - Baskin anatomy: clitoral innervation not localized
  - Schober QOL follow-up: numbness increases with each surgery

## Invalid Assumptions II

- n gender is determined by genital appearance
- n gender is determined by parental conviction
- n gender is determined by female fertility
- n gender is determined by hormones
- n gender can be assigned based on surgical convenience

## Invalid Assumptions III

- n sex assignment requires surgery
- n emotional health possible only with surgery
- n for women, fertility more important than sexual sensation

## New Model: Psychology-centered

- n careful dx is urgent, not emergency
- n base tentative sex label on dx, presentation
  - can't predict gender 100%
- n MD initial approach to parents critical

## Honesty and openness

- n Counselors must be professional, experienced
  - knowledge of intersex adults
- n counseling, peer support for parents
- n counseling, peer support for patients
  - age-appropriate
  - adolescence brings difficult dev. tasks

## Surgery when *medically* necessary

- n urinary function
- n cancer risk

## Surgery at patient's request

- n physically grown
- n psychologically prepared
- n socially mature
- n fully informed

## Change of sex role at patient's request

## Reform medical nomenclature

- n "hermaphrodite" stigmatizing, misleading
- n "male," "female": Victorian idea of true sex
- n "true," "pseudo"
  - emotionally loaded, imply authenticity
- n base nomenclature upon developmental process

## Photos of intersex people as humans!

- n current pix are dehumanizing
- n intersex people as humans

## Follow Up!

- n for better tentative sex assignments
- n for better counseling approaches
- n for better surgical options at pt's request

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