

Standards Of Care For Harry Benjamin's Syndrome (HBS)



Medicine - Clinical Practice

HarryBenjaminSyndrome-info.org

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Abstract. The 'Harry Benjamin's Syndrome – Standards of Care' (HBS-SOC) is regarded as the new model for transsexual treatment and healthcare. Advancements in scientific research have yielded new findings that place transsexualism into a new category – that of Congenital Neurological Intersex. The HBS-SOC were formulated to consolidate the current knowledge regarding transsexualism and to provide a new paradigm to the global community at-large as well as practitioners specializing in HBS fields of service.

As the global population increases, so do cases of Harry Benjamin's Syndrome. However, it remains, per capita, a rare occurrence. Nonetheless HBS continues to be misunderstood, miscategorized, and inconsistently treated. Thus it is imperative to revise the current understanding of the fundamental nature of HBS and to redefine protocols for its effective treatment.

The acceptance of 'transgender' as an accepted social group has entrapped HBS (formerly 'transsexualism') under its umbrella, an action that is both unwarranted and unwanted. To help remove HBS from the transgender stigma and clarify it as a unique medical condition with a biological cause, we offer the HBS-SOC.

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I. Introduction

In the recent past Harry Benjamin's Syndrome (HBS) has been known as transsexualism, an obsolete term that neither accurately describes nor effectively communicates the complexities inherent to its condition. Today it is recognized as an intersex condition.

Harry Benjamin's Syndrome (HBS) is named in honor of the man who recognized the condition as a medical anomaly and advanced its treatment, Dr. Harry Benjamin. It was through his compassionate understanding and abiding interest that he came to recognize and define the condition. Over the course of his career, with dedication and vision, he developed and refined treatment methods to help people affected by what we now know as HBS.

It should be clearly understood that Harry Benjamin's Syndrome is not a choice, any more than Turner's Syndrome or Lou Gehrig's Disease (ALS) is a choice. Nor is it a result of nurture (i.e. artificially developed through parenting and environment). HBS is an inborn biological anomaly, a natural occurrence, as are all intersex conditions.

II. Purpose

The purpose of the Standards of Care for Harry Benjamin's Syndrome (SOC-HBS) is to codify HBS and establish a new paradigm for the effective management of patients afflicted with Harry Benjamin's Syndrome (HBS).

III. Scope

The Standards of Care for Harry Benjamin's Syndrome (SOC-HBS) are intended to serve

- as an educational aid - to present a clear understanding of HBS to the global community at large.
- as a reference source - to offer coherent medical treatment guidelines for health care professionals.
- as a motivating source for change - to factually challenge current treatment methods and suggest improvements.
- as a summons - to petition the scientific community to refresh and broaden research efforts and to advance essential perspective.

Professionals are encouraged to utilize this document to enhance their understanding of HBS and develop appropriate and effective treatment strategies for their patients.

Persons born with HBS, their families, social institutions, and legal bodies may use the SOC-HBS to gain a comprehensive understanding of HBS and an awareness of the principles by which it is currently understood.

IV. Principles

Principle 1: Harry Benjamin's Syndrome is an intersex condition.

HBS is a biological variation in human sexual formation where the sex indicated by the phenotype and the genotype is opposite the morphological sex of the brain.

Principle 2: Persons born with Harry Benjamin's Syndrome seek rehabilitation of their phenotype and endocrinology to accord with their sex.

Persons born with HBS have both male and female characteristics. Sex (i.e. gender identity or awareness of sex) is irreversibly determined by the structure of the brain. Sex organs (genitals) are determined genetically through chromosome selection during conception and gestation. Harry Benjamin's Syndrome is the untenable situation arising from the contradiction of having mismatched brain sex and sex organs (genitals). HBS, then, is concerned with altering one's physical sex to match one's brain sex; it is about recognizing and respecting gender norms.

Principle 3: Harry Benjamin's Syndrome is an ancient and persistent form of human nature, not a modern discovery.

Historical narratives show that Harry Benjamin's Syndrome has existed throughout history; HBS is not new to this century. It should be recognized as a natural phenomenon, another form of the human condition. It is separate and distinct from sexuality. Most adamantly it

must not be confused with displays of modern day gender-variant expressions.

Principle 4: Persons born with Harry Benjamin's Syndrome have the right to obtain adequate medical care for their condition as soon as they request it, without discrimination.

Harry Benjamin's Syndrome is a legitimate medical condition and it should be given the same consideration and respect and rigorous approach as any other medical condition. All public and private health systems should respond to requests for assistance to the best of their ability and with all due dignity and respect to the person making the request, without discrimination.

Principle 5: Persons with Harry Benjamin's Syndrome have the right to preserve their identity, intimacy, and privacy regarding all aspects of their condition and situation.

Labels, apart from 'male' or 'female', are unacceptable and dehumanizing. The application and use of labels such as 'pre-op transsexual' dishonors HBS sufferers and serves no purpose other than as expressions of ignorance. Medical care and treatment should be soberly and professionally conducted, without adding stigma.

Principle 6: Harry Benjamin's Syndrome is an innate, life-threatening condition; its treatment is essential for survival.

Due to common misperceptions there is a social stigma that surrounds HBS. Fed and sustained by ignorance, HBS causes societal and family discrimination, pressure, and stress. Many of those suffering from this syndrome have been forced to accept ridicule and denial from family, friends, co-workers, and other segments of society, which understandably exerts a deep dysphoria. Social withdrawal, depression and suicide (attempted or actualized) are not uncommon reactions to the trauma induced by such conditions.

Following Sex Affirmation Surgery suicide rates among HBS patients fall to the societal average, and depression typically resolves by degrees until normalcy returns. This in itself is an indication of the profound restorative effects of HBS treatment protocols.

Principle 7: Harry Benjamin's Syndrome patients have the right to function in society with full dignity and respect, including functional legal rights, regardless of their incongruous, albeit temporary, physical circumstances during corrective treatments.

Widely disparate local, regional, national, and international laws constrict the rights and legal status of HBS patients. It is suggested that jurisprudence and the various legal systems be reviewed and updated to confer legal status for HBS persons experiencing the 'Real Life Test' phase of their affirmation process, and while on hormone preparation be allowed to change functional documentation that would allow them to work and function in their true sex.

This documentation should be provided with a term limit suggested to coincide with the actual 'Real Life Test' period. Such temporarily amended documentation should only be provided by the appropriate agencies after the request is authenticated with a physician's diagnosis confirming Harry Benjamin's Syndrome.

Unless one has had Sex Affirmation Surgery (SAS), birth certificates should be neither permanently changed nor temporarily amended. That would be a contradiction of facts and lead to societal and legal confusion. Birth certificates should reflect the actual physical sex of an individual, not the attitude or presentation of a personality.

V. Definition and Etiology

Harry Benjamin's Syndrome (HBS) is a congenital intersex condition that develops in the early stages of pregnancy affecting the process of sex differentiation between male and female. This happens when the brain develops as a certain sex but the rest of the body takes on the physical characteristics of the opposite sex.

We now know that the brain is the organ that defines sex; that is, sex is determined by brain structure, not by genitalia. Therefore girls born with Harry Benjamin's Syndrome have a female brain sex but her genitals are male. Boys born with this condition have female genitalia even though their brain sex is male.

The difference between Harry Benjamin's Syndrome and most other intersex conditions is that there is no apparent pre-birth evidence nor, to date, are there any absolute, definitive diagnostic procedures.

Diagnosis of HBS is thus delayed until its effects become symptomatic. Sadly, this results in raising babies in the wrong gender role.

VI. Epidemiological Considerations

Research studies have shown anywhere from 1 out of 500 births to 1 out of 30,000 births are born with Harry Benjamin's Syndrome. In view of such widely variable statistics, it must be acknowledged that factual numbers remain elusive. Until such time as a controlled study can authoritatively be undertaken, preferably on a global scale using factually formulated criteria, such data remains uncorroborated.

Verifiable (i.e. repeatable and reproducible) epidemiological research is encouraged in order to establish a statistical foundation from which to advance further research.

Regardless of the lack of verifiable statistical ratios it can certainly be agreed upon that HBS, as a rare intersex anomaly, affects only an exceedingly small portion of the population.

VII. Diagnostic Nomenclatures

Harry Benjamin's Syndrome was known in the past under many different names, transsexualism being the most common. However, Harry Benjamin's Syndrome is not transsexualism, at least not under the current definition of transsexualism provided by the ICD-10 which considers it a mental condition with a psychological cause.

As has been shown, Harry Benjamin's Syndrome is a physical condition indicative of a fetal anomaly and to continue to categorize it as a mental condition is outdated and unfair; it wrongly denies patients with Harry Benjamin's Syndrome essential medical care by placing them under inappropriate standards of care.

In 1980 Transsexualism was introduced in the Diagnostic and Statistical Manual of Mental Disorders (DSM-III) and fourteen years later, in 1994 it was changed to Gender Identity Disorder (DSM-IV). It is supposed to be revised again in 2007.

We hope that the condition will then be renamed Harry Benjamin's Syndrome for the reasons we explain in the next section. We propose these differentiated levels of diagnosis:

- HBS in Children (below age 12)
- HBS in Adolescents (below age 18)
- HBS in Adults
- HBS along with other intersex conditions
- HBS along with other neurological conditions
- HBS not otherwise specified

VIII. Classification and Terminology

Harry Benjamin's Syndrome is a neurologically induced intersex condition and as such must be classified as an intersex condition along with other intersex conditions, and not among mental disorders. Should Harry Benjamin's Syndrome be denied an intersex classification then it should be classified along other rare medical conditions not related to any mental disorder.

Harry Benjamin's Syndrome is named after Dr. Harry Benjamin, a visionary physician and pioneer researcher who contributed significantly to the recognition, understanding, and treatment of HBS, which he knew in his time as transsexualism. His medical biography stands alone in contemporary medical history as the most significant, most respected, and most authoritative relative to this

syndrome. (See also his published work *The Transsexual Phenomenon*, Benjamin, 1966.)

Harry Benjamin's Syndrome and its acronym HBS are the preferred replacements for current terminologies because they lend historical substance and a coherent medical essence to the condition, whereas other terminologies instill distortion or possess misleading connotations.

Basic Terminology associated with Harry Benjamin's Syndrome:

Harry Benjamin's Syndrome (HBS)

- Previously defined

Hormone Replacement Therapy (HRT)

- Individualized program of hormone treatment based on the assessed endocrinological needs of each patient. HRT mimics, or 'replaces', the otherwise missing hormone-producing glands or organs of the affirmed sex.

Sex Affirmation Surgery (SAS)

- The primary surgical removal/alteration/reconstruction of genitals/sex organs to match those of the affirmed sex.

Affirmation, Affirmation process

- Formerly referred to as 'transition', affirmation is the realization process wherein the HBS patient moves from living their assumed (extrinsic) gender role to living their affirmed (intrinsic) gender role.

Intersex, Intersexed, Intersexual (IS)

- Having characteristics of both male and female including, in varying degrees, reproductive organs, secondary sexual characteristics, and/or sexual behavior resulting from a sex chromosome abnormality or a hormonal imbalance during embryogenesis.

Reflections about other terminologies commonly used in the past:

- Transsexual

The contemporary term for Harry Benjamin's Syndrome is transsexualism, coined by sexologist Magnus Hirschfeld in the 1920's. The term transsexual is a combination of two words: trans + sexual. The word trans is a Latin prefix which means across, beyond, through. The word sexual is an adjective derived from the Latin sexualis which means relating to, or associated with, sex or the sexes.

The term transsexual was originally conceived as a means to confer a biological cause for homosexuality and other anomalous sexual behavior. It soon became synonymous with those who 'change sex'. It seemed suitable. Unfortunately, the term's original meaning has since been eclipsed and co-opted by the media as well as non-transsexual persons, creating inextricable confusion. Its continued use in today's world has been rendered untenable for those who could otherwise legitimately claim its usage.

The term transsexual commonly evokes a connection to sexual orientation that does not exist. Sex and sexual orientation are unrelated characteristics. Thus, inclusion of the word 'sex' presupposes undesired connotations.

The term bears enough of a superficial similarity to transvestism and transgenderism so that it is easily confused. This inappropriate correlation of completely unrelated phenomenon serves to further corrupt the term's original intent.

Worst of all, the term transsexual is commonly used as a label which, in itself, is dehumanizing and insulting. Referring to someone as a transsexual rather than a man or a woman makes it easier to think of them as being 'other than' or 'less than'. People with Harry Benjamin's Syndrome are people who happen to have a particular medical problem; it is a birth defect, not an identity.

Used as an adjective, as in 'transsexual man' or 'transsexual woman', the term is no better. Rather than clarifying the nouns 'man' and 'woman', the adjective transsexual only serves to obfuscate them. Is it any wonder, then, why most people are confused about whether the appropriate noun for any particular individual is 'man' or 'woman'?

As a final note, it must be understood that HBS survivors who have completed the affirmation process have endured unimaginable adversity for the chance to live normal, uncompromising lives - the type of life everyone else takes for granted. The term transsexual becomes inappropriate after the physical transformation has been completed, for then it is no longer a question of 'being between' or 'crossing between' the sexes as the term transsexual implies. They are whole in mind and body, and there is no further need to refer to them for the purpose of identification as anything other than a 'woman' or 'man'.

- Transsexualism, Transsexuality

Among the lay public there is still a great deal of emotionally charged stigma attached to the idea of transsexuality. It is often mistakenly considered by many people to be a lifestyle, or an extension of one's personality when, in fact, it is not.

Nor do people with Harry Benjamin's Syndrome change sex - they don't become the opposite sex - they already are a determinate sex, as is everyone. Sex is not genitals or reproductive organs, sex is distinctly imprinted in the brain; it comes 'built in'. **It cannot be reinforced enough: once biologically hard-wired into the brain during gestation and birth,**

sex cannot be changed.

As has been shown HBS is a biologically induced manifestation and therefore a natural phenomenon. It is observable elsewhere in the animal kingdom, not just in humans.

Corroborative research findings have further confirmed the existence of biological markers for Harry Benjamin's Syndrome. These findings, in parallel with updated terminology, are very important historical developments. Such advancements are proving very liberating and encouraging to those now living with the syndrome.

- Gender Identity Disorder

Other common terms such as Gender Identity Disorder (GID) and Gender Dysphoria, although sounding suitably clinical, identify Harry Benjamin's Syndrome as being a psychiatric condition. This is not the case at all; Harry Benjamin's Syndrome is purely a physical problem and can only be treated by fixing the body.

While it may be obvious that there are associated psychological symptoms resulting from the pressures of living an inauthentic existence and the myriad social problems thus created, they must not be mistaken for the condition itself.

While psychiatric evaluation is an essential diagnostic aid, it should not be seen as the main focus for remediation of, or 'curing', HBS. Attempts to alter brain sex (i.e. one's gender identity) to match their bodies have been spectacularly unsuccessful. The only proven and reliably effective treatment for HBS is to fix the body.

Falsely implying that people with Harry Benjamin's Syndrome are mentally ill or deluded is not only inappropriate when viewed in the light of the current state of knowledge, it is incompetent. Harry Benjamin's Syndrome can no longer be acknowledged or treated as a mental disorder. To continue this practice is to foster ignorance and prolong suffering.

- Transgender

Transgender has become popular as an all-inclusive term for a wide variety of extremely disparate groups, especially amongst the queer community. By inference it includes transsexuals and those with HBS. This connection is both unwarranted and counterproductive. It is far too broad a category to say anything useful or specific, and implies similarities that do not exist. Using such a vague 'catch all' term to describe someone tells you nothing about them, or who or what they might be.

Perhaps because of its laundered verbiage (i.e. removal of the word 'sexual') the term transgender has been co-opted by the lay public, the media, and even professional care givers themselves as the politically correct term to use when referring to or describing various forms

of queer, gender nonspecific, or gender deviant personalities, behaviors, or the persons themselves. Likewise, the term has been adopted by the queer community (i.e. gay, lesbian, bisexual) as a cleaner, non-threatening umbrella term that includes all forms of deviant gender expression. Few who use the term can offer a clear, precise definition of what transgender means, so it continues to perplex even those who use it.

Alone, this single term has caused the greatest harm towards understanding HBS simply by inveigling its confusing, nonspecific, user-defined connotation into the public's consciousness. The cumulative effect of its now popular usage has literally stifled any attempt to redirect or reestablish the legitimacy of HBS as a true syndrome. The term transgender is anathema to HBS and its use should be avoided at all costs.

Preference for SAS (Sex Affirmation Surgery) above other surgical terms:

The term Sex Affirmation Surgery (SAS) is preferable to the currently popular alternative terms Sex Reassignment Surgery (SRS) or Gender/Genital Reassignment Surgery for describing the operation used to help correct the anatomies of people with Harry Benjamin's Syndrome.

There is certainly no reassignment of sex or gender since the brain sex (gender) of the person born with HBS has already been immutably established in the womb and is already as it should be. Sex Affirmation Surgery therefore speaks about the process of affirmation, i.e. correction of a physical defect, not about reassignment of sex or gender.

IX. Requirements for Professionals

The following are the minimum qualifications for specialized competence in the diagnosis and treatment of Harry Benjamin's Syndrome:

1. Doctorate degree of Medicine (MD).
2. Master's degree, or its equivalent, in a clinical behavioral science field.
3. Specialized training in the assessment, management and treatment of Harry Benjamin's Syndrome.
4. Continuing education in the discipline of Harry Benjamin's Syndrome, which may include attendance at professional meetings, workshops, seminars, or participation in areas of research related to Harry Benjamin's Syndrome.

X. Diagnosis and Treatment

The medical community of today is perfectly capable of successfully treating Harry Benjamin's

Syndrome but still lacks effective diagnostic tools. This failure can be traced to a lack of information and research data about this condition, therefore leaving doctors with outdated treatment options mired in the myths of the past.

Once diagnosed, treatment options are often greatly complicated by the negative intervention of health insurers. Historically, the health care insurance industry has done substantial harm to HBS sufferers by denying or obstructing required and necessary treatment.

We are beginning to see the winds of change regarding global recognition of HBS and its need for medical inclusion within the health care community. Research, though painfully slow, is gaining ground in forging awareness and concern towards a more comprehensive and compassionate understanding of HBS. Slowly, inroads to viable treatment options are being laid around the world as countries are coming to grips with the reality of HBS and the recognition that it can, and must, be effectively managed – to the benefit of all.

Diagnosis

Harry Benjamin's Syndrome is distinctive in that it is a self-diagnosed condition; that is, people with HBS are exclusively aware of its presence and the onus for articulating its existence lies with them.

Regrettably, most HBS patients are aware of it from early childhood, long before they are old enough to articulate its essence. As a result, they invariably suffer an existence of prolonged isolation and confusion. Ironically, once capable of understanding the nature of their dilemma, they are almost universally stigmatized into keeping it secret until such time as they can no longer tolerate suffering its destructive effects.

It is at this point of discovery and disclosure that every effort must be made to confirm the HBS patient's self-diagnosis. Currently there is no diagnostic test or procedure that can unequivocally prove a patient's contention that their brain sex is opposite from their genital sex. There are, however, systematic methods for validating and confirming the syndrome's existence.

Once a patient seeks help, diagnosis must be competently approached through objective medical and psychological/psychiatric examination to rule out other possibilities, of which there are many. Upon confirmation, medical treatment must be immediately offered, and without undue delay.

In most cases, it is difficult to give a diagnosis before late infancy or pre-adolescence, although countries like the Netherlands are very advanced in diagnosing and treating this syndrome. Thanks to the hard work of Cohen-Kettenis, people living in the Netherlands are able to start the treatment before puberty.

Treatment

The alignment of the HBS patient's body to their brain sex is a complex process that is not easily undertaken, nor instantly gratifying. Though HBS patients unhesitatingly welcome the severity of the challenge, it may best be approached through realistic goal setting. Regardless of expectations, successful treatment requires time, resources, and commitment. Treatment will include:

- ✓ Hormone Replacement Therapy (HRT)
- ✓ Sex Affirmation Surgery (SAS)
- ✓ Therapeutic Counseling, if required

Hormone Replacement Therapy (HRT)

In order to prepare the body for SAS, hormone treatments are typically the first step. It is advisable to visit an endocrinologist, preferably one skilled in the treatment of HBS and who has up-to-date information regarding such treatment.

Levels of current, pre-HRT sex hormones should be tested. Slight variations from the average levels are often found; sometimes stronger variations are noticed but are less frequent.

Genotype and HY antigen testing, if optionally undertaken, may reveal matching genotype and phenotype, as well as HY antigen response, for the affirming sex (brain sex) but are neither predictable nor conclusive indicators.

Additionally, physical features such as hypogonadism should be noted, as well as any other morphologic characteristics that might match the affirming sex of the patient, prior to beginning HRT.

As an example, many girls with Harry Benjamin's Syndrome already have clearly feminine physical forms and bone structure prior to starting HRT, but such physical characteristics are secondary in nature and should not be assessed as primary diagnostic indicators.

These secondary sex characteristics (physical features) appear in only a minority of HBS patients. While inconclusive on the whole, their occurrence does add to the evidence that HBS is a physical, rather than a mental, condition.

Sex Affirmation Surgery (SAS)

Sex Affirmation Surgery is the surgical process of altering one's genital sex to match their brain sex. In successfully completing this process the HBS patient is 'affirming' their sex; that is, they have affirmatively taken charge of their lives to surgically correct their genital anomalies.

Therapeutic counseling (re-establishing psychological comfort)

Early treatment of Harry Benjamin's Syndrome can have a profound, deeply restorative effect. However, there is no 'magic bullet' treatment that can guarantee immediate or prolonged relief from the cumulative effects of living with the syndrome.

Each HBS patient is certain to experience some degree of psychological ill-effects from having endured years of living in the wrong sex role, even if outward appearances hint to the contrary. It should be kept in mind by diagnosticians and patients alike that a period of psychological readjustment following onset of treatment is considered normal and should not be unexpected.

The adjustment period varies widely, depending on the degree and extent of effects and the patient's ability to process them. In some cases counseling is not required; medical treatment alone reinstates the patient to wholeness by eliminating the cause of psychological distress and imbalance. There are no established 'normal' parameters.

It cannot be stressed too strongly that, other than for initial diagnostic purposes, long-term psychological or psychiatric follow up is strongly contraindicated for patients with HBS unless there are other indications for such follow-up.

To whatever degree psychological scarring is or is not present, it must be clearly understood that such indications are an artifact of living with HBS, not its cause. It is essential to remember that Harry Benjamin's Syndrome is a biological anomaly, not a mental disorder!

XI. Treatment of HBS in Children

Treatment of Harry Benjamin's Syndrome in children is a complicated task requiring the careful diagnostic assessments of a child-specialist mental health professional. During the diagnostic period the individual child's gender identity and gender role behaviors, family dynamics, past traumatic experiences, and general psychological health are separately assessed.

Following a confirming diagnosis, a pediatric endocrinologist can start Hormone Replacement Therapy in the child patient. HRT should only be administered in cases where persistent and consistent feelings of body incongruity in the child have been established and confirmed for longer than 6 months.

Sex Affirmation Surgery (SAS) can then be considered as an option to correct the physical problem. However, the child HBS patient should wait until they reach onset of puberty to apply for SAS.

Given the lack of corroborative biological testing for HBS, utmost caution must be employed before allowing early surgeries. The surgical procedure itself is better undertaken after the

body and genitals have reached adolescence.

XII. Treatment of HBS in Adolescents

There is a growing body of evidence that the administration of sex hormone blocking agents in teenagers can, and do, delay somatic changes associated with puberty. While such early action may be viewed as vital by both patient and diagnostician toward the successful future development of secondary sex characteristics, it must be dealt with conservatively because gender identity development can rapidly evolve in unexpected directions.

To minimize the risk of error, HRT should be withheld for 6 months from the initial date of diagnosis, during which time the patient's progress should be assessed in greater depth. Sex Affirmation Surgery can, and should, be considered after one year from the initial HBS diagnosis.

To qualify for this treatment the adolescent patient should meet the following criteria:

- (1) Throughout childhood they have demonstrated an intense pattern of an incongruous nature towards their body's sexual identity, resulting in an aversion to expected gender role behaviors.
- (2) Sexual identity discomfort has significantly increased with the onset of puberty.
- (3) The family consents to, and participates in, corrective therapy.

Hormonal treatment should be conducted in two phases. In the initial phase females should be provided an antiandrogen (which neutralize testosterone effects only) or an LHRH agonist (which stops the production of testosterone only), and males should be administered sufficient androgens, progestins, or LHRH agonists (which stops the production of estradiol, estrone, and progesterone) to stop menstruation.

After these changes have occurred and the adolescent's mental health remains stable, females may be given estrogenic agents and males may be given higher masculinizing doses of androgens.

Medications used in the second phase (estrogenic agents for females, high dose androgens for males) produce irreversible changes. Consequently, this must be considered as a critical evaluation and treatment parameter.

XIII. Treatment of HBS in Adults

After diagnosis of HBS, HRT can be immediately started. Psychological follow up, as a rule, should then be stopped. Long-term psychological care or psychiatrist care based on HBS

alone is contraindicated. One year after the initial diagnosis of HBS, SAS can be completed providing the patient meets the requirements for surgery noted below.

Hormone Replacement Therapy plays an important role in the anatomical and psychological sex affirmation process for properly diagnosed adults with HBS. These hormones are medically necessary for rehabilitation in their affirmed sex. When physicians administer androgens to males and estrogens, progesterone, and/or testosterone-blocking agents to females, patients feel and appear more like members of their true sex.

After a thorough medical history, physical examination, and laboratory examination, the physician should again review the likely effects and side effects of this treatment, including the potential for serious, life-threatening consequences. The patient must have the cognitive capacity to appreciate the risks and benefits of treatment, have his/her questions answered, and agree to medical monitoring of treatment.

In the absence of any other medical, surgical, or psychiatric conditions, basic medical monitoring should include:

- (1) Regular physical examinations relevant to treatment effects and side effects.
- (2) Vital sign measurements before and during treatment
- (3) Weight measurements and laboratory assessment.

For females receiving estrogen treatment, the minimum laboratory assessment should consist of a pretreatment free testosterone level, fasting glucose, liver function tests, and complete blood count, with re-assessment at three month intervals and annually thereafter. A pretreatment prolactin level should be obtained and repeated at 1, 2, and 3 years. If hyperprolactemia does not occur during this time, no further measurements are necessary.

Females should also be monitored for breast cancer and strongly encouraged to engage in routine breast self-examination. As they age, they should be monitored for prostatic cancer.

For males receiving androgens, the minimum laboratory assessment should consist of pre-treatment liver function tests and complete blood count with reassessment at 3-month intervals and yearly thereafter. Yearly palpation of the liver should be considered. Patients should be screened for glucose intolerance and gall bladder disease.

Males who have undergone mastectomies who have a family history of breast cancer should be monitored for the disease.

Hormonal treatment, when medically tolerated, should precede any genital surgical interventions. Satisfaction with the hormone's effects consolidates the person's identity as a member of her/his gender. Dissatisfaction with hormonal effects may signal ambivalence about proceeding to surgical interventions.

In females, hormones alone often generate adequate breast development, precluding the need for augmentation mammoplasty.

XIV. Requirements for Sex Affirmation Surgery and Breast Surgery

Prior to obtaining SAS or breast surgery, the following minimum guidelines are strongly encouraged. While many may feel these guidelines are too rigid of an imposition, they nonetheless give both patient and caregiver ample opportunity to assess the correctness of the HBS diagnosis. It is understood that, as with any medical treatment protocol, the process of assessment and validation may reveal the need for departures from the norm.

Recommended requirements for SAS or breast surgery are:

- (1) One year on Hormone Replacement Therapy after HBS diagnosis.
- (2) One year of successful continuous full time living in her/his affirmed sexual identity.
- (3) Awareness of the cost, required lengths of hospitalizations, likely complications, and post surgical rehabilitation requirements of various surgical approaches before any procedures are begun.
- (4) Awareness of the options of different competent surgeons.
- (5) Physician consent form for surgery.

Sex Affirmation Surgery is the most important and effective treatment to correct the underlying problem of HBS. The surgeon should be a gynecologist, urologist, plastic surgeon, or general surgeon, and Board-Certified as such by a nationally known and reputable association.

The surgeon should have specialized competence in genital reconstructive techniques as indicated by documented supervised training with a more experienced surgeon. Even experienced surgeons in this field must be willing to have their therapeutic skills reviewed by their peers. Willingness and cooperation with peer review is essential. This includes attendance at professional meetings where new ideas about techniques are presented.

Ideally, the surgeon should be knowledgeable about more than one of the surgical techniques for genital reconstruction so that the surgeon will be able to choose the ideal technique for the individual patient's anatomy and medical history. When surgeons are skilled in only a single technique, they should so inform their patients and refer those who do not want or are unsuitable for this procedure to another surgeon.

Prior to performing any surgical procedures, the surgeon should have all medical conditions

appropriately monitored and the effects of the hormonal treatment upon the liver and other organ systems investigated. This can be done alone or in conjunction with medical colleagues. Since pre-existing conditions may complicate genital reconstructive surgeries, surgeons must also be competent in urological diagnosis. The medical record should contain written informed consent for the particular surgery to be performed at least 24 hours in advance of surgery.

XV. Genital, Breast, and Other Surgery for the Female Patient

Surgical procedures may include orchiectomy, penectomy, vaginoplasty and augmentation mammoplasty. Vaginoplasty requires both skilled surgery and postoperative treatment. The three currently proven techniques are:

- (1) penile skin inversion
- (2) pedicled rectosigmoid transplant
- (3) free skin graft to line the neovagina

Augmentation mammoplasty should be performed prior to vaginoplasty only after the physician prescribing hormones, the surgeon, and the HBS patient consensually agree that natural breast development after undergoing hormonal treatment for two years is not sufficient for comfort in the social gender role.

Other surgeries that may be performed to assist feminization include:

- (1) reduction thyroid chondroplasty
- (2) suction-assisted lipoplasty of the waist
- (3) rhinoplasty
- (4) facial bone reduction
- (5) face-lift
- (6) blephoroplasty

Patients who elect voice modification surgery should do so after all other surgeries requiring general anesthesia with intubations are completed in order to protect their vocal cords.

XVI. Breast and Genital Surgery for the Male Patient

Surgical procedures may include mastectomy (chest reconstruction), hysterectomy, salpingo-

oophorectomy, vaginectomy, metoidioplasty, scrotoplasty, urethroplasty, and phalloplasty.

Current operative techniques for phalloplasty are varied. The choice of techniques may be restricted by anatomical or surgical considerations. If the objectives of phalloplasty are a neophallus of good appearance, standing maturation, sexual sensation, and/or coital ability, the patient should be clearly informed that there are both several separate stages of surgery and frequent technical difficulties, which require additional operations. Even the metoidioplasty technique, which in theory is a one-stage procedure for construction of a microphallus, often requires more than one surgery. The plethora of techniques for penis construction indicates that further technical development is necessary. Patients may undergo hysterectomy and salpingo-oophorectomy prior to phalloplasty.

The mastectomy procedure is usually the first surgery performed, but for some patients it is the only surgery undertaken. When the amount of breast tissue removed requires skin removal, a scar will result and the patient should be so informed.

Long-term follow-up with the surgeon is recommended in all patients to ensure an optimal surgical outcome. Surgeons who are operating on patients who are coming from long distances should include personal follow-up in their care plan and then ensure affordable, local, long-term aftercare in the patient's geographic region. Postoperative patients may also incorrectly exclude themselves from follow-up with the physician prescribing hormones, not recognizing that these physicians are best able to prevent, diagnose, and treat possible long term medical conditions that are unique to hormonally and surgically treated patients. Postoperative patients also have general health concerns and should undergo regular medical screening according to recommended guidelines.

XVII. HBS along with other conditions

Section to be developed in future drafts.

HBS along with other intersex conditions.

HBS along with other neurological conditions.

XVIII. Artificially Induced HBS

One situation in which the cause of Harry Benjamin's Syndrome is quite clear is the sexual mutilation of children or infants. This most often occurs with intersex infants whose genitalia are ambiguous. It is common practice that the intersex infant is operated on to make them conform more closely to a sex arbitrarily chosen by a doctor or parent, with no possibility of consent or regard for the infant's brain structure or gender identity.

It can also occur if a male infant's penis is accidentally mutilated or severed, and where it is

deemed easier to surgically transform him into a female than to reconstruct or reattach the penis.

Research, as well as anecdotal evidence from the affected people themselves, has disclosed that people in these situations are, as a rule, unhappy living with the results of presumptuous and arbitrary decisions wrongly made on their behalf. It is not uncommon for them to seek out and revert to their actual gender (true brain sex) later in life.

This tragic scenario can, and should, be avoided by allowing the child to develop and mature autonomously to the point where self-actualization of his or her true sex can be realized. Only then, with commensurate precautions having been ensured, should appropriate corrective surgery be undertaken.

"Standards Of Care (SOC) for Harry Benjamin Syndrome". The [Harry Benjamin Syndrome Informational Resource](#) (2007).

PDF Downloads

[Letter To The American Psychological Association](#)

[Standards of Care For Harry Benjamin's Syndrome](#)

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