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Standards Of Care For Harry Benjamin's Syndrome

(SOC-HBS)

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shb-info.org

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Contents:

I. Introduction.

The purpose of the Standards of Care for Harry Benjamin's Syndrome (SOC-HBS) is to articulate a general consensus about the medical management of Harry Benjamin's Syndrome (HBS). Professionals may use this document to understand the parameters within so that they may offer assistance to those with problems arising from HBS. Persons born with HBS, their families, and social institutions may use the SOC-HBS as a means to understand the current sometimes misguided tendencies of treatment of patients by professionals.

All readers should be aware of the limitations of research in this area and of the hope that the clinical uncertainties will be resolved in the future through further scientific investigation. It should be carefully understood that Harry Benjamin's Syndrome is not "a choice" or a result of nurture; it is an inborn anomaly as are all intersex conditions. In this paper all references to sex apply to brain sex of the HBS pre-surgical patient.

II. Principles.

Principle 1.

Harry Benjamin's Syndrome is a biological variation in human sexual formation –an intersex condition- 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 are born with male and female characteristics, and they seek rehabilitation of their phenotype and endocrinology to accord with their dominant sexual identity, an identity which is determined by the structure of the brain. Harry Benjamin's Syndrome is about matching one's physical sex with one's brain sex, it is not about sexual behavior. Harry Benjamin's Syndrome is about being a particular sex, not about "doing it". It is also about recognising gender norms, not challenging them.

Principle 3.

Harry Benjamin's Syndrome is an ancient and persistent part of human nature, not a modern discovery. Persons born with Harry Benjamin's Syndrome have a legitimate medical condition and it should be given the same consideration and respect and rigorous approach as any other medical condition.

Principle 4.

Persons afflicted with Harry Benjamin's Syndrome have the right to obtain adequate medical care for their condition as soon as they request it. All public health systems should respond to this request to the best of their ability and with all due dignity and respect to the person making the request.

Principle 5.

Persons with Harry Benjamin's Syndrome have the right to preserve their intimacy and privacy in respect to their condition and situation. Any labels naming or suggesting the social or sexual stages during or after corrective treatment must be absolutely avoided when and if possible. Other labels for identity, apart from Male or Female, are not acceptable. Medical care and treatment should be soberly conducted and without stigma.

Principle 6.

Harry Benjamin's Syndrome is a Life-threatening condition; not only because of its nature but also because of the social stigma that surrounds it and the resulting ignorance that causes societal and family discrimination.

Principle 7.

Harry Benjamin's Syndrome's sufferers have the right to function in society with full dignity, respect and legal rights, regardless of their temporary physical situations during corrective treatments, therefore all international legal systems should adjust to this as a feasible policy and guarantee it for all patients with HBS.

Principle 8.

Harry Benjamin's Syndrome should not be confused with gender variant conditions or with sexual orientation issues. It is a physical anomaly curable with hormonal-surgical intervention.

Principle 9.

It is unethical to discriminate in providing medical care to HBS patients based on their sexual orientation, physical appearance, HIV status, race or

religion.

III. Definition and Aetiology.

Harry Benjamin's Syndrome is an intersex condition developed in the early stages of pregnancy affecting the process of sexual 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. The difference between this and most other intersex conditions is that there is to date no apparent pre-birth evidence and the symtoms only become evident after the baby is born or even as late as adolescence. Harry Benjamin's Syndrome (HBS) is a congenital intersex condition that develops in the womb, involving the differentiation between male and female. Therefore a girl with Harry Benjamin's Syndrome would have a female brain sex but her genitals would appear male. Boys born with this condition have female genitalia even though their brains are male. So far it is impossible to diagnose this condition at the moment of birth resulting in the babies to be raised in the wrong gender role.

We now know that the brain is the only part of the body that can define one’s sex. Therefore, one's true sex is determined by the structure of the brain, not by the genitalia. Gender identity is hard-wired in the brain and in deeper CNS structures. The main difference between Harry Benjamin's Syndrome and some other intersex conditions is that there is no apparent evidence at the moment of birth making it possible for doctors to diagnose it.

IV. Epidemiological Considerations.

It is believed that 1 child out of every 500 is born with Harry Benjamin’s Syndrome. Recent studies show that the prevalence of corrective surgeries

on HBS patients in the U.S. is at least on the order of 1:2500, and may be as much as twice that value. Therefore, the intrinsic prevalence of HBS in women might be on the order of ~1:500. These results appear to be consistent with studies of HBS prevalence in recent studies in other countries.

V. Diagnostic Nomenclatures.

Harry Benjamin's Syndrome was known in the past under many different names, Transsexualism being the most common. Some have even added transsexualism as a sub-set of transgender and that of course was never intended to be included under that umbrella term when transgender was coined. However, Harry Benjamin's Syndrome is **not** Transsexualism (or any variation of Transgenderism). At least not under the current definition of Transsexualism provided by the ICD-10.

Harry Benjamin's Syndrome is still incorrectly classified as Transsexualism today by the ICD-10. "Transsexualism" is classified as a mental disorder with a psychological cause. Harry Benjamin's Syndrome is a physical condition indicative as a fetal anomaly. There is no relationship between these conditions. Maintaining such an outdated policy only denies patients with Harry Benjamin's Syndrome adequate medical care and societal understanding. It can also often place them under the inappropriate medical 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 2008.

We hope that the condition will be named **Harry Benjamin's Syndrome** for the reasons we explain in the next section. We strongly urge to remove Harry Benjamin's Syndrome from the Diagnostic and Statistical Manual of Mental Disorders.

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.

VI. Classification and Terminology.

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

Harry Benjamin's Syndrome is named in honor of Dr Harry Benjamin, a pioneer in the research of this condition. He was the physician who contributed much to the understanding and recognition of this condition. It was through his efforts the entire medical community came to understand HBS was unrelated to homosexuality. **Harry Benjamin's Syndrome, (HBS),** is greatly preferable to other terms because it lacks the misleading connotations and inaccurate meanings they possess.

Basic Terminology associated with Harry Benjamin's Syndrome:

Harry Benjamin's Syndrome. (HBS)
Hormone Replacement Therapy. (HRT)
Sex Affirmation Surgery. (SAS)
Affirmation and Affirmation's process.
Intersex, Intersexed, Intersexual. (IS)

Reflections about other terminologies commonly used in the past:

a. Transsexualism – Transsexuals.

The most well-known term for Harry Benjamin's Syndrome is Transsexualism (coined by sexologist Magnus Hirschfeld in the 20's). Unfortunately there are several problems with it. Simply including "sex" in the name attracts undesirable attention, and the word strongly implies a connection with sexual orientation that does not exist. It's too similar to "transvestism", a completely unrelated phenomenon (men who enjoy wearing women's clothing don't have much in common with men who were born with female anatomy and are very unhappy about it) that bears enough of a superficial similarity to cause much confusion. Also, labelling people with Harry Benjamin's Syndrome with the term "transsexual" is a bad thing. Saying that people *are* transsexuals is dehumanizing, and makes it easier to think of them as being "other". People with Harry Benjamin's Syndrome are *people*, who happen to have a particular medical problem; it is not their identity, and they are not specimens of the condition. Use as an adjective is not much better; with "transsexual man" or "transsexual woman", it's too easy for "transsexual" to be interpreted as "pretend", and for some reason many people seem to be confused about whether the appropriate noun for any particular individual is "man" or "woman".

The term "transsexual" is a combination of two words: "trans" + "sexual". The word "trans" is a Latin prefix which means across, beyond, through, so as to change. In modern English it means on, or to the other side of, across, beyond. The word "sexual" is an adjective derived from the Latin sexualis, and it means of, relating to, or associated with sex or the sexes. When these two words are combined, the reason the term has been applied to some individuals becomes apparent. Now well, those called "transsexuals", must make many adjustments to overcome difficult obstacles. Somehow it seems unfair to burden people with labels which no longer seem appropriate when they have made changes, adjustments, overcome obstacles, had surgery, and taken their places in society in roles in which they are comfortable. In their minds, it is no longer a question of being between or crossing between the sexes, as the term "transsexual" implies. And certainly, at that point, they have not need not desires to have surgical alteration of their genitals. If others needs to refer to them for the purpose of identification, then they should use the terms "woman" or "man".

b. Transsexuality.

There is a great stigma associated to Transsexuality: This is considered to be a "lifestyle choice" for many people or even a kind of "expansion" of one's personality, and the term "transsexuality" itself reinforce even more this so deeply rooted stigma about Harry Benjamin's Syndrome. That's why

the findings of biological markers for the syndrome in parallel with the update of the terminology in use, are so liberating. Transsexuality is a natural phenomenon in the animal kingdom and is there where to speak about transsexuality or transsexuals is adequate, but it is not adequate to use this same terminology with human beings, with persons. Simply because the persons aren't amphibious changing sex continually in a "natural" way, and of course is not a choice they made neither. People with Harry Benjamin's Syndrome do not change sex, they don't become the opposite sex, they already are of a determined sex -determined by its brain structure, which already is how it should be, and it cannot be "changed".

c. Gender Identity Disorder.

The other common terms "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 (leaving aside the social problems and pyschological effects resulting from having such a physical deformity, of course), and can only be treated by fixing the body. While psychiatric evaluation is useful in *diagnosing* the syndrome, attempts to alter the sufferers' genders to match their bodies have been spectacularly unsuccessful. Falsely implying that people with Harry Benjamin's Syndrome are mentally ill or deluded is not a good way to promote understanding and acceptance of the condition.

d. Transgender.

"Transgender" has become popular recently as an all-inclusive term for a wide variety of extremely disparate groups, especially amongst the queer community This is not a positive development, as it is far too broad a category to say anything useful, and implies similarities that do not exist. It's like having a word that means "plays chess, is asian, or has cancer" - using it to descibe someone tells you nothing about them.

And about the preference to use SAS (Sex Affirmation Surgery) above other terms:

The term "Sex Affirmation Surgery" (SAS) is preferable to the alternatives of "Sex Reassigment Surgery" (SRS) or "Gender 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 gender involved, and it only involves one aspect of physical sex, which is not a binary, either-or characteristic. The sex of the brain is already as it should be, and HRT corrects other sexual characteristics. For men, HRT can even go a little way towards correcting the genitalia, though nowhere near the complete development that occurs in the womb. It is about Affirmation (or correction of a physical defect), not about transition or change.

VII. Requirements for Professionals.

The following are the minimal credentials for special competence with HBS:

1. Doctorate degree of Medicine (MD).
2. A master's degree or its equivalent in a clinical behavioral science field.
3. Specialized training and competence in the assessment, management and treatment of Harry Benjamin's Syndrome (not in transsexualism per se, gender
identity disorder or other conditions usually associated with those under the transgender umbrella).
4. Continuing education in the treatment of Harry Benjamin's Syndrome which
may include attendance at professional meetings, wokshops, or seminars, or participating in research related to Harry Benjamin's Syndrome.

VIII. Diagnosis and Treatment.

Psychological follow up is very useful for a proper diagnosis of this condition and its physical treatment afterwards can correct it completely. The early treatment of Harry Benjamin's Syndrome can eliminate virtually all the symptoms of the condition although it can be reasonably assumed that having suffered the long terms effects of untreated Harry Benjamin Syndrome may result in the need for some proper and effective counseling

to eliminate or diminish the lingering and possibly damaging after effects.

In order to properly realign the person's body to its proper brain sex the treatment will include Hormonal Replacement Therapy (HRT) and Sex Affirmation Surgery (SAS).

Most of the medical community of today is perfectly prepared to successfully treat Harry Benjamin's Syndrome but is still lacking the quality diagnosis caused by the lack of information and research updates about this condition therefore leaving doctors equating treatment with the myths of the past.

It is advisable to visit an endocrinologist and give him or her up to date information about Harry Benjamin's Syndrome, this way you will be opening the door to receive more objective treatment. 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.

It's important to remind everyone that Harry Benjamin's Syndrome is a physiological condition and not psychiatric, even though the help of a psychologist can be very useful for the patient, especially the younger ones in the initial evaluation and proper diagnosis. The treatment of this condition includes HRT and SAS. Visiting a psychiatrist or a therapist for evaluation should be required but not as a long-term treatment parameter unless other issues not related to HBS exist. Then if the patient is diagnosed as having HBS then the patient should be referred to an endocrinologist for hormone preparation for SAS followed by referral to a competent surgeon.

Long-term psychological follow up (other than for diagnosis purpose only) and any kind of psychiatrist treatment are strongly contraindicated for patients with HBS unless there are other issues that need to be resolved.

Genotype and HY antigen testing are recommended. Genotype and phenotype match in the vast majority of cases, and HY antigen should be negative in most females with HBS, and it should be positive in most males with HBS –as happens with most men without HBS too.

Sex Hormones levels should also be tested. Slight variations from the average levels are often found. Occasionally greater variations are noticed but they are less frequent.

Additional physical features such as hypogonadism should be noted as well as any other observed morphologic characteristics that might match the true sex of the person (the brain sex) prior to beginning HRT. As an example, many girls with Harry Benjamin's Syndrome have clearly feminine physical forms and bone structure prior to starting HRT. These are considered secondary indicators and although often found they should not be used per se as criteria for a diagnosis of HBS. Their occurrence does add to the evidence that HBS is a physical, rather than mental condition.

IX. Treatment of HBS in Children.

The task of the child-specialist mental health professional is to provide careful diagnostic assessments of children with HBS. This means that the individual child's gender identity and gender role behaviors, family dynamics, past traumatic experiences, and general psychological health are separately assessed. A pediatric endocrinologist can then start Hormone Replacement Therapy in the child after 6 months of the initial diagnosis of HBS, but only in those cases with persistence and consistence of the feeling of body incongruity for longer than 6 months. Sex Affirmation Surgery (SAS) can be considered then to correct the physical problem but the child should wait until he/she is at least 12 or 13 years old (depending on each individual development) to enter the following diagnostic of “HBS in Adolescents” in order to apply for SAS. –Given the lack of biological testing for HBS we should be very cautious with early surgeries. For the surgical procedure itself it is better to be done after the body and genitals had reached the adolescence period as well –sometimes the pre-adolescence period.

X. Treatment of HBS in Adolescents.

As soon as HBS is diagnosed in teenagers there is growing clinical experience in administering sex hormone blocking agents prior to age 16

to delay the somatic changes of puberty. However adolescents with HBS should be dealt with conservatively because gender identity development can rapidly and unexpectedly evolve. HRT can be started after 6 months of the diagnosis of HBS. Sex Affirmation Surgery can and should be considered after one year of the initial HBS diagnosis.

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

(1) Throughout childhood they have demonstrated an intense pattern of body's sexual identity's incongruity and aversion to expected gender role behaviors;

(2) Sexual identity discomfort has significantly increased with the onset of puberty;

(3) The family consents and participates in the 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 and high dose androgens for males, produce irreversible changes.

XI. Treatment of HBS in Adults.

After diagnosis of HBS is complete, HRT can be immediately started. Psychological follow up should be then 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 done if 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 selected 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: serial physical examinations relevant to treatment effects and side effects, vital sign measurements before and during treatment, weight measurements, and laboratory assessment. For those receiving estrogens, the minimum laboratory assessment should consist of a pretreatment free testosterone level, fasting glucose, liver function tests, and complete blood count with reassessment at 6 and 12 months 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. For those receiving androgens, the minimum laboratory assessment should consist of pretreatment liver function tests and complete blood count with reassessment at 6 months, 12 months, and yearly thereafter. Yearly palpation of the liver should be considered. Patients should be screened for glucose intolerance and gall bladder disease. Females undergoing estrogen treatment should be monitored for breast cancer and encourage in engage in routine self-examination. As they age, they should be monitored for prostatic cancer. Males who have undergone mastectomies who have a 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. Hormones alone often generate adequate breast development, precluding the need for augmentation mammaplasty.

Requeriments for Sex Affirmation Surgery and Breast Surgery:

1. Six months on Hormone Replacement Therapy after HBS diagnosis.

2. One year of successful continuous full time living in her/his affirmed sexual identity.

3. Demonstrable knowledge of the cost, required lengths of hospitalizations, likely complications, and post surgical rehabilitation requirements of various surgical approaches.

4. Awareness of different competent surgeons.

5. A 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 urologist, gynecologist, 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 are 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 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.

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

Surgical procedures may include orchiectomy, penectomy, vaginoplasty and augmentation mammaplasty. Vaginoplasty requires both skilled surgery and postoperative treatment. The three techniques are: penile skin inversion, pedicled rectosigmoid transplant, or free skin graft to line the neovagina. Augmentation mammaplasty may be performed prior to vaginoplasty if the physician prescribing hormones and the surgeon have documented that breast enlargement 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: reduction thyroid chondroplasty, suction-assisted lipoplasty of the waist, rhinoplasty, facial bone reduction, face-lift, and blephoroplasty. Voice modification surgery: Patients who elect this procedure should do so after all other surgeries requiring general anesthesia with intubation are completed to protect their vocal cords.

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 micturition, 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 indicate 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 is 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 the hormonally and surgically treated. Postoperative patients also have general health concerns and should undergo regular medical screening according to recommended guidelines.

XII. HBS along with other conditions.

Section to be developed in future drafts.

HBS along other intersex conditions.
HBS along other neurological conditions.

XIII. 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 physically intersexed infants, where the individual is operated on to make them conform more closely to a sex chosen by a doctor with no possibility of consent or regard for their brain structure/ gender indentity. It can also occur if a male infants's penis is acidentally damaged or removed, and it is easier to surgically transform him into a female and raise him as such than to reconstruct the penis. It is common for people in these situations to be very unhappy with what was done to them, and revert to living according to their actual gender later in life.

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