Changing the name of diabetes insipidus: a position statement of The Working Group for Renaming Diabetes Insipidus

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Abstract

‘What’s in a name? That which we call a rose/By any other name would smell as sweet.’ (Juliet, from Romeo and Juliet by William Shakespeare). Shakespeare’s implication is that a name is nothing but a word and it therefore represents a convention with no intrinsic meaning. Whilst this may be relevant to romantic literature, disease names do have real meanings, and consequences, in medicine. Hence, there must be a very good rationale for changing the name of a disease that has a centuries-old historical context. A working group of representatives from national and international endocrinology, nephrology and pediatric societies now proposes changing the name of ‘diabetes insipidus’ to ‘arginine vasopressin deficiency (AVP-D)’ for central etiologies and ‘arginine vasopressin resistance (AVP-R)’ for nephrogenic etiologies. This editorial provides both the historical context and the rationale for this proposed name change.

Reasons for changing a disease name

Understanding of disease processes is a dynamic field, with rapidly evolving concepts of pathophysiology based on emerging molecular and genetic data. Consequently, a newer understanding of the pathophysiology is one of the major reasons for renaming diseases. In endocrinology, appreciation of hyperprolactinemia as the common pathophysiology underlying many different clinical situations causing galactorrhea and amenorrhea led to the effective abandonment of many previous eponymous names for these conditions such as Chiari-Frommel...
syndrome, Forbes-Albright syndrome, Ahumada-del Castillo syndrome, etc. (1). A second reason is based on historical discoveries that a previous eponymous name for a syndrome was inappropriately attributed to an individual who was not the first or even the most significant person involved in the description of the syndrome (2). A third reason is later appreciation of medically unethical behaviors of individuals with diseases eponymously named for them, as characterized by the renaming of Reiter's syndrome to ‘reactive arthritis’ and Wegener's granulomatosis to ‘granulomatosis with polyangiitis’, because of the association of the eponymous physicians with Nazi antihumanitarian crimes (3, 4). The first three of these reasons for changing disease names make a strong case for detaching eponyms from disease processes whenever possible (5). However, endocrinologists would be loath to abandon the eponyms of Addison, Cushing, Hashimoto and others for their unique and seminal contributions to our understanding of endocrine disease processes. However, a fourth reason for renaming diseases is when traditional disease names lead to confusion between pathophysiologicaly different processes, leading to treatment errors and consequent adverse outcomes for patients. This latter reason represents the major impetus to change the name of diabetes insipidus at this time.

**Rationale for changing the name of diabetes insipidus**

There are multiple reasons to change the name of diabetes insipidus at this time. First and foremost, although the terms mellitus and insipidus do differentiate between the clinical characteristics of these two very different causes of polyuria, and clearly are not eponyms, the use of the common term ‘diabetes’ in both has unfortunately led to confusion for both patients and their caretakers. This confusion with diabetes mellitus has been to the detriment of patients with diabetes insipidus when they are under the care of non-endocrine specialists. Some physicians and nurses do not appreciate the difference between these two very different disorders. In several patients with central diabetes insipidus, desmopressin treatment was withheld with serious adverse outcomes, including death (9). This has led to high-profile litigation cases and coroners’ inquests involving the police, with wide media coverage. Subsequent to these unfortunate but avoidable cases, national safety alerts, surveys amongst endocrinologists and a global task force consisting of a wide range of senior clinicians involved with the care of patients with diabetes insipidus have led to a strong impetus to change the name of the condition. Second, patients with diabetes insipidus strongly support changing the name of the condition. Second, patients with diabetes insipidus have led to a strong impetus to change the name of the condition. Second, patients with diabetes insipidus have led to a strong impetus to change the name of the condition. Second, patients with diabetes insipidus have led to a strong impetus to change the name of the condition. Second, patients with diabetes insipidus have led to a strong impetus to change the name of the condition. Second, patients with diabetes insipidus have led to a strong impetus to change the name of the condition. Second, patients with diabetes insipidus have led to a strong impetus to change the name of the condition. Second, patients with diabetes insipidus have led to a strong impetus to change the name of the condition. Second, patients with diabetes insipidus have led to a strong impetus to change the name of the condition.
resulting clinical confusion affected the management of their condition, e.g. repeated blood sugar measurements or prescription of medication for diabetes mellitus during hospitalization. Finally, we believe the names of medical disorders optimally should reflect the underlying pathophysiology, which in the case of diabetes insipidus is now well known to be deficient secretion and/or end-organ effects of the hormone arginine vasopressin (AVP). Hence, for all the above reasons, the working group proposes that the name diabetes insipidus should be changed to ‘arginine vasopressin deficiency (AVP-D)’ for central etiologies and ‘arginine vasopressin resistance (AVP-R)’ for nephrogenic etiologies, and this proposal has been endorsed by the following societies represented by the working group members: Endocrine Society, European Society of Endocrinology, Pituitary Society, Society for Endocrinology, European Society for Paediatric Endocrinology, Endocrine Society of Australia, Brazilian Endocrine Society and the Japan Endocrine Society and is under review at several other societies.

**Implementation of the name change for diabetes insipidus**

In order to ease the transition in terms of online searches and avoid confusion in the literature, we propose that for several years we keep the previous name in parentheses. Therefore, we will begin using the terms AVP-deficiency (cranial DI) and AVP-resistance (nephrogenic DI) in manuscripts and chapters. Once the transition is complete, it is likely that the parenthetic term will be lost, albeit people can still use it if they wish. In addition, we have initiated a request to the ICD Coordination and Maintenance Committee to have the ICD-11 coding changed to reflect the new names.

We fully recognize that changing a name for a long-standing disease is not easy. But just as the rheumatologists who proposed the name change of granulomatosis with polyangiitis (Wegener’s granulomatosis) (4), we hope our medical colleagues will recognize and accept the above rationale for making this change, both in the interest of scientific accuracy, but more so for the benefit and safety of our mutual patients with diabetes insipidus so that their disease and its treatment will no longer be confused with diabetes mellitus.

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The authors declare that there is no conflict of interest that could be perceived as prejudicing the impartiality of this guideline.

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