

## The Difficulty of Pituitary Disorders

a report by

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In the past 15 years, the clinical appreciation of the impact of pituitary disorders has accelerated at a gratifying, yet dangerously expeditious, manner, leaving little time for the advancing knowledge and proper medical practice guidelines to percolate through the medical/patient/public sector and so allow for uniform improvement in understanding and patient care. Medicine, hormonal replacements, surgical and radiological treatment options flourish, to the great satisfaction of the inventing scientists/academic medical practitioners, while leaving the great majority of patients both un- and under-treated—and in too many instances, un- or under-diagnosed.

At the same time, the overwhelming ‘reach’ of pituitary dysfunction on the patient’s life and his/her family entity, whether hyper- or hyposecretory, ‘non-functioning’, gonadotrophic, incidentally discovered or sought adenomas, because of patient complaints may also include true tumors, or another of myriad disorders, diseases, cysts, and lesions plaguing the patients and confounding his/her physicians. Conflicting conclusions most often lead to conflicting and ineffective treatment, and an apparently ‘never-ending treadmill’ of symptoms, complaints, and misdirected treatment leads to enormous patient/societal costs and deep conflict between patients and their physicians/surgeons. Patients too often despair of finding competent help, are denied further testing or treatment by their insurance companies, and eventually ‘settle’ for disability benefits (the dole) or other forms of governmental/charitable existence, without reaching a satisfactory answer to their ailments.

The situational issues would, perhaps, not be so alarming were it not for myriad discoveries about hormonal effects on mental, sexual, metabolic, reproductive, and bone health. The often overlapping issues are both conflicting and very costly, while public health concerns also come into play. The sheer number of patients and their great variety of complaints and constellation of symptoms will not for long go unchallenged or unappreciated. Fortuitously, hormonal disorders/diseases are not *de novo* concerns like AIDS, avian flu or severe acute respiratory syndrome (SARS); the endocrine community has studied and concerned itself with the issues at hand for many generations, but their work goes largely under-

appreciated in the great medical scheme of things. Firstly, the endocrine medical community is not one for raising alarms or issuing warnings. Secondly, the issues are too complicated for the cursory coverage by the lay media.

### Clinical Features

It is both confusing and sometimes disturbing to realize that weight gain, obesity, and eating disorders are not always associated with over-indulgence and an inability and/or unwillingness to control one’s urges, but may indeed be linked to hormonal hyper- or hyposecretion by the pituitary gland. Infertility and/or lack of libido can be linked to hormonal insufficiencies or excess. Classically, a psychological assessment would view eating and sexual disorders from a strictly learning and/or behavioral perspective or due to dysfunctional relationship patterns or childhood trauma, and would ignore the potential physiological aspect altogether.

Emotional/mental healthcare has, however, undergone a major ‘overhaul’ since the days of Jung and Adler. The concept that myriad emotional disorders, from depression to bi-polar disorder to apathy, may be related to a hormonal imbalance is new for the psychological community. Hormonal imbalance as a potential etiological factor—not just a difficult childhood or stressful environment and relationships—is just beginning to become part of the clinical assessment protocol. Additionally, a potential relationship between psychological and/or physical trauma and imbalances in the endocrine system is slowly being recognized and is yet to be fully understood. Psychologists, family therapists, social workers, and others are now learning to broaden their understanding of the role of the endocrine system and deepen diagnostic skills to include more interaction with medical professionals, who can appropriately rule out pituitary and hormonal imbalances.

The largest, almost intractable, difficulty facing both patients and the medical community, is an apparent unwillingness or inability to agree on fairly simple issues, such as symptoms, definitions, and classifications. At the one side of the spectrum are the learned, well-reasoned words of Dr Harvey Cushing, who, in 1913, said:

# DECEMBER IN THE DESERT 2006

*a comprehensive conference covering the many aspects of hormonal health*

*Dr. Harvey Cushing, the famous pioneering neurosurgeon/physician, had this to say in 1913:  
"It is quite probable that the psychopathology of everyday life hinges largely on the discharge  
of the ductless gland upon the nervous system."*

## The Pituitary Network Association

invites you and yours to:

## DECEMBER IN THE DESERT 2006



Conference for Patients and their Families and Physicians,  
Nurses, Mental Health Providers, Health Insurance Leaders,  
Hospital Administrators and those who "suspect" but still don't know,  
as well as the health conscious general public;  
December 7 thru 10, at the fabulous Westin Rancho Mirage  
in Rancho Mirage, California

### HEALTH CARE PROVIDERS:

Do you have patients for whom you can't seem to find answers? They tell of symptoms, but what is the problem?

### PATIENTS AND FAMILY:

Are you at your wits end-tired of looking for answers in "all the wrong places?"

**"How I'm feeling and what my doctor is telling me..." Bridging the gap!**

**The *un*-diagnosed, *under*-diagnosed patient, and the diagnosed patient.**

**Two Sets of Issues: Medical and Psychological. How do we reconcile the two?**

The main conference goal is to reduce the time between onset of symptoms and diagnosis so patients can live life to the fullest. Family hormonal meetings will explore patients' symptoms, plus the range of medical, surgical and radiological treatments. And the latest information on long-term follow-up care, maximizing quality of life. We'll delve into the complications that impact physical and emotional health, including mood, fertility, sexual function, diabetes, osteoporosis, and accelerated heart disease.

The conference program will be divided into four segments or Quads, each with two components:

1.) The diagnosed pituitary patient; 2.) the un-diagnosed or under-diagnosed pituitary patient. Each segment will be led by recognized, highly respected faculty with many years of research and clinical experience in their field. The speakers and presenters will provide unique, often first hand experiences.

Dr. Roger Guillemin, of the Salk Institute in La Jolla, California, winner of the Nobel Prize in medicine, will be one of the featured speakers, and present the topic: "Neuroendocrinology. How did it start and where are we now?" Also, patients' perspectives of pituitary disease will be shared by speakers such as patient advocate Sharmyn McGraw.

New this year will be the addition of mental health professionals as speakers and attendees. Marriage and family therapists, psychologists and other mental health providers are key components to early identification of hormonal difficulties as well as an important part of a good treatment team.

Dr. George Chrousos, Professor of Pediatric Medicine at the University of Athens, Greece and formerly the National Institutes of Health will also be among the featured speakers. He has educated the world regarding pediatric hormonal medicine, Cushing's disease and the mind-body interaction. Dr Chrousos will be honored at the elegant conference banquet Friday evening, as the Gentle Giant for 2006!

Co-hosts California Association of Marriage and Family Therapists, and University Of California, San Francisco will be providing speakers, facilitators and CEU/CME Credits.

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For conference agenda and details, please visit: <http://media.pituitary.org/DecDes06/>

To register online visit: <http://www.pituitarynetwork.org/events/>

or contact Barbara Schriber and register today at (805) 499-9973 or [barbara@pituitary.org](mailto:barbara@pituitary.org)

*“It is quite probable that the psychopathology of everyday life depends largely upon the effects of the discharge of the ductless gland upon the nervous system.”*

Or Plato, who said:

*“That as you ought not to attempt to cure the eyes without the head, or the head without the body, so neither ought you to attempt to cure the body without the soul; and this,” he said, “is the reason why the cure of many diseases is unknown to the physicians of Hellas, because they are ignorant of the whole, which ought to be studied also; for the part can never be well unless the whole is well.”*

Although thousands of years separate the two, their wisdom and learning is the same. Though the physiological part of endocrinology is ‘hard’ science and the psychological part is ‘soft’ science, the two simply have to come together in order to make any major, meaningful advances in pituitary endocrinology diagnoses and treatment. Whereas the definition and diagnosis of diabetes mellitus, for instance, is measured in quantifiable terms of blood, and thyroid disorders are evaluated and judged in similar ways, the definition and determination of pituitary/hormonal diseases is left almost solely to the judgment of individual medical practitioners, who feel free to include or discount patients’ reported symptoms and complaints at will. To some medical personnel, a headache is a meaningful symptom of a disorder—to others it is merely an incidental happening, with little or no relationship to either mass-effect or hormonal hypersecretion. Mood swings and depression to most clinicians are recognized as a ‘minor’ issue, usually treated with antidepressants and a recommended change of lifestyle.

Family and general relationship functioning is a key indicator to overall patient functioning yet is often ignored both pre- and post-diagnosis and during treatment. Family members often observe, and are deeply affected by, patient symptoms of increased anger outbursts, sexual dysfunction, depression, and changes in a patient’s overall sense and awareness of themselves. The impact of pituitary and hormonal dysfunction on the family cannot be overstated. Assessing marital, family, and relationship functioning as yet another key indicator for diagnosis and treatment has largely been ignored.

Loss of libido, erectile dysfunction (ED), irregular or missing menses are frequently regarded as issues of extraneous, non-pituitary/hormonal origin, and are rarely used as a basis for further exploration or a specific diagnostic work-up. Again, change of lifestyle and avoidance of stress are the popular medical recommendations. Those on the psychological/ mental health side of medicine may well be attempting to treat

physiological symptoms and disorders, caused by hyper- or hyposecretion of hormones, often caused by a tumor in pituitary patients without making any attempts to link the rather distinct ‘constellation’ of symptoms to an underlying physiological origin.

However, once a diagnosis of a pituitary adenoma is made, or of a cyst or other related lesion, the neurosurgeon will often insist this is his/her prescribed territory, and if a successful resection is made the surgeon will, too often, tell the patient that he/she is ‘cured’ and should go home, recover and get on with life. Sadly, maybe months or years later, the patient is complaining of new, often worse, symptoms, not understanding why the cure did not last. Endocrinologists, on the other hand, too often insist that their prescribed regimen of medication is sufficient, and the patient should just resign her/himself to ‘being grateful’ for life, regardless of the quality. Only in very rare instances do the two ‘opposing’ views recognize the need for psycho-social intervention and even medical treatment for mental, behavioral, family/ relationship, or cognitive dysfunction.

One cannot help but believe that once a commonality of understanding is reached, treatment and solution will follow in rapid order. It is clear from studies conducted over the last century that secretory pituitary tumors are prevalent, by a magnitude of hundreds of times over those numbers previously believed. Non-secretory (previously referred to as non-functional) tumors may indeed be gonadotrophs, first and foremost attacking the sexual wellbeing and functioning of the patients before progressing to the emotional/mental health states. In addition, there are a remarkably large array of diseases affecting the pituitary, from hypophysitis to craniopharyngiomas. All such conditions can result in a profound impact, manifested by serious and life-altering health problems.

### Call for Unity

A five-way partnership must be formed in order to set the stage for solid success and create a forward momentum in the care of patients with pituitary disorders. Patients, together with their family/endocrinologist/surgeon/and mental healthcare providers must be part of the diagnostic and ‘after acute care’ stage to insure not only a chemical cure, but also the healing so vital to the patient’s ability to return to his/her place in family and society. ■

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