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## ANNOUNCEMENT

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### A Registry for Resistance to Thyroid Hormone

A worldwide registry for subjects with Resistance to Thyroid Hormone (RTH) has been established at the recommendation of the attendees of the First International Workshop on RTH held July 10 to 11, 1993, in Cambridge, UK. The registry currently contains data on 404 individuals belonging to 169 families fulfilling the diagnostic criteria of RTH.

Currently, the Registry provides the following information in approximate chronological order of publication\*: (1) family identification (ID) by "F" number assigned to each family in a recent review on the subject,<sup>†</sup> as well as that given in the original publication; (2) subject ID; (3) sex; (4) names of key author(s) of the initial descriptive publication or the name of the referring physician; (5) ethnic origin; (6) reason for investigation; (7) chief complaint leading to thyroid studies; (8) associated conditions; (9) somatic defects, if any; (10) type of prior treatment (currently incomplete); (11) serum total T<sub>4</sub> levels (before and after treatment when available); (12) serum T<sub>3</sub> values (before and after treatment when available); (13) basal serum TSH levels (before and after treatment when available); (14) serum T<sub>3</sub>/T<sub>4</sub> ratios (ng/μg) before and after treatment when available; (15) thyroïdal radioiodide uptake (RAIU) after and before treatment when available; (16) serum total reverse T<sub>3</sub> (after and before treatment when available); (17) serum thyroglobulin (TG) (after and before treatment when available); (18) the genetic defect when known (mutation in the thyroid hormone receptor (TR) β gene, shown as a single letter amino acid code before (normal) and after (altered) codon‡; (19) affinity of the mutant TRβ for T<sub>3</sub> (expressed as fraction of the wild type TRβ); (20) author of key publication; and (21) references to publications related to each family.

The information in this Registry is updated regularly. Future updates will include birth date of subjects, and free T<sub>4</sub> levels (expressed as % of the upper limit of normal for the laboratory in which the determination was performed), type of treatment, and date treatment will be completed.

The Registry can be accessed by navigating to the University of Chicago gopher server (gopher.uchicago.edu) and selecting the Medicine subfolder in which the RTH Registry is found or directly locating the server "snakeoil.bsd.uchicago.edu." We have included a comma-delimited ASCII version of the Registry that can be retrieved and loaded into a spreadsheet for easier viewing.

This Registry is maintained by Drs Samuel Refetoff and Roy Weiss of the Endocrinology Section of the Department of Medicine, University of Chicago, with the assistance of Dr Paolo Beck-Peccoz from the University of Milan. All published cases of RTH except for some classified as PRTH\* have been entered. The registry is a "read only" file.

We encourage comments concerning the Registry and especially correction of errors. These can be e-mailed to *rth-registry@medicine.bsd.uchicago.edu*. All published cases will be automatically updated into the Registry on a semiannual basis.

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\*Note that not all subjects formerly classified as having isolated pituitary resistance to thyroid hormone (PRTH) have been entered in the Registry.

<sup>†</sup>Refetoff S, Weiss RE, Usala SJ: The syndromes of resistance to thyroid hormone. *Endocr Rev* 14:348-399, 1993

<sup>‡</sup>Beck-Peccoz P, Chatterjee VKK, Chin WW, et al: Nomenclature of thyroid hormone receptor β-gene mutations in resistance to thyroid hormone: Consensus statement from the first workshop on thyroid hormone resistance, July 10-11, 1993, Cambridge, UK. *J Clin Endocrinol Metab* 78:990-993, 1994