ranged from 1 week to 6 years with Hi-F duration of 3 days to 5 years. 24-hour urine free cortisol (UFC) levels were 17 - 301 times the upper reference range (RR) during Hi-F periods. During Eu-F, lowest UFCs were within RR in 9 patients and subnormal in 3. Hypokalemia occurred in 11 patients with Hi-F; increasing values paralleled movement to Eu-F.

Conclusion: Patients with possible ectopic ACTH-secretion and CCS may pose a diagnostic challenge: clinical and biochemical evidence of hypercortisolemia may not be present, depending on the timing and/or duration of hypercortisolism. Furthermore, test results may inappropriately suggest Cushing's disease if performed after less than 8 weeks of hypercortisolism, or with recent eucortisolism. Thus, weekly UFC measurement may facilitate diagnosis of cyclical Cushing's syndrome and determine appropriate timing of dynamic testing such as inferior petrosal sinus sampling. Potassium may be a useful marker to determine when medical treatment can be tapered or stopped.

1. Meinardi JR, et al. Eur J Endocrinol. 157:245, 2007.

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PEDIATRIC PUBERTY, TRANSGENDER HEALTH, AND GENERAL ENDOCRINE

European Registries for Rare Endocrine Conditions (EuRRECa): Results from the Platform for E-reporting of Rare Endocrine Conditions (e-REC)

Salma R. Ali, MRCPCH[1], Jillian Bryce, PhD[1], Martine Cools, MD[2], Thomas Danne, MD[3], Mehul T. Dattani, MD, FRCPCH, FRCP[4], Olaf M. Dekkers, MD, PhD[5], Olaf Hiort, MD, PhD[6], Agnes Linglart, MD, PhD[7], Irene Netchine, MD, PhD[8], Anna Nordenstrom, MD, PhD[9], Attila Patocs, MD, DSc[10], Alberto M. Pereira, MD, PhD[11], Luca Persani, MD, PhD[12], Nicole Reisch, MD[13], Arlene Smyth, -[14], Zdenek Sumnik, PhD[15], Domenica Taruscio, MD[16], W. Edward Visser, MD, PhD[17], S Faisal Ahmed, MD, FRCPCH[1].

[1]University of Glasgow, Glasgow, United Kingdom, [2]Ghent University Hospital, Ghent, Belgium, [3]Diabetes Center AUF DER BULT, Hannover, Germany, [4]UCL Institute of Child Health, London, United Kingdom, [5]Leiden University Medical Ctr., Leiden, Netherlands, [6]University of Luebeck, Luebeck, Germany, [7]APHP, Bicetre Paris Sud, Le Kremlin Bicetre, France, [8]Sorbonne Universite, Hopital des Enfants Armand Trousseau, Paris, France, [9]Karolinska University Hospital, Stockholm, Sweden, [10]Semmelweis University, Budapest, Hungary, [11]Leiden University Medical Center, Leiden, Netherlands, [12]University of Milan & IRCCS Istituto Auxologico Italiano, Milan, Italy, [13]Med. Klinik und Poliklinik IV, Klinikum der Universitat Munchen, Munich, Germany, [14]Office for Rare Conditions, Glasgow, United Kingdom, [15]Motol University Hospital, Prague, United Kingdom, [16]National Centre for Rare Diseases, Istituto Superiore di Sanita, Rome, Italy, [17]Erasmus Medical Centre, Rotterdam, Netherlands.

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Background EuRRECa (European Registries for Rare Endocrine Conditions) is a group of web-based projects that work closely with the European Reference Network (ERN) for Rare Endocrine Conditions (endo-ern.eu) and helps the ERN with inventorying its clinical activity. To understand the number of new encounters of rare conditions within this network, it has launched an e-reporting programme for rare endocrine conditions (e-REC) that are covered within this network. **Methods** 46 endocrine centres within 18 countries volunteered to participate in e-REC from July 2018 to June 2019. An electronic reporting 'card' developed through REDcap was issued monthly to enquire whether clinicians had encountered a new case of any condition within the 8 Endo-ERN main thematic groups (MTGs). **Results** On a monthly basis over 1 year, a median of 14 (range 11, 21) paediatric centres and 13 (11, 25) adult centres actively reported cases. A median of 53 (22, 80) paediatric cases and 96 (42, 250) adult cases were reported monthly. Amongst paediatric cases, conditions within the Sex Development and Maturation (SDM) theme were most commonly reported comprising 38% of all reported conditions, with XY, DSD being the most commonly reported condition (24% of cases). Amongst adults, Pituitary and Thyroid conditions were most commonly reported, 34% and 26% of all conditions, respectively. Amongst conditions within the Pituitary group, pituitary adenoma was the most commonly reported condition (74% of cases) and non-metastatic thyroid carcinoma was the most commonly reported condition (95% of cases) amongst the Thyroid group. In children, the median number of cases reported per centre was 21 (9, 32) for conditions affecting SDM. In adults, a median of 37 (6, 75) Pituitary and 22 (5, 80) Thyroid cases were reported per centre. **Conclusion** e-REC is a simple, yet effective, platform that can be used to capture information on new encounters with patients with several rare conditions and can be adapted to serve the needs of other discrete networks that are interested in understanding the occurrence of rare conditions.

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UNDERSTANDING AND TREATING PEDIATRIC GROWTH DISORDERS

Somatrogon Growth Hormone in the Treatment of Pediatric Growth Hormone Deficiency: Results of the Pivotal Pediatric Phase 3 Clinical Trial.

Cheri L. Deal, MD, PhD, FRCPC[1], Aleksandra Pastrak, MD, PhD[2], Lawrence A. Silverman, MD[3], Srinivas Rao Valluri, PhD[4], Michael Paul Wajnrajch, MD, MPA[5], Jose Francisco Cara, MD, BSc[6].

[1]University of Montreal, Montreal, QC, Canada, [2]OPKO Health, Miami, FL, USA, [3]Goryeb Children's Hospital, Morristown, NJ, USA, [4]Pfizer, Inc., New York, NY, USA, [5]Pfizer Inc, New York, NY, USA, [6]Pfizer Global Pharmaceuticals, New York, NY, USA.

OR10-06

Background: Somatrogon (hGH-CTP) is a long acting recombinant human growth hormone (rhGH; somatropin) in development for once weekly treatment of children with growth hormone deficiency (GHD). Somatrogon contains the amino acid sequence of hGH and three copies of the carboxy-terminal peptide (CTP) derived from human chorionic gonadotropin. A 12 month phase 2 trial of once weekly Somatrogon vs daily Genotropin in children with GHD demonstrated that 0.66 mg/kg/wk of Somatrogon had a similar benefit - risk profile as 0.24 mg/kg/wk of Genotropin. The open label extension of this phase 2 study has generated an additional 5 years of longitudinal efficacy