

# The ESPN/ERA-EDTA Registry

## Considerable variations in GH policies in pediatric ESRD.

M. van Huis, M. Bonthuis, K.J. van Stralen, F. Schaefer, K.J. Jager, J.W. Groothoff.  
On behalf of the ESPN/ERA-EDTA Registry, Amsterdam Medical Centre, Amsterdam, the Netherlands  
For more information: k.j.vanstralen@amc.uva.nl

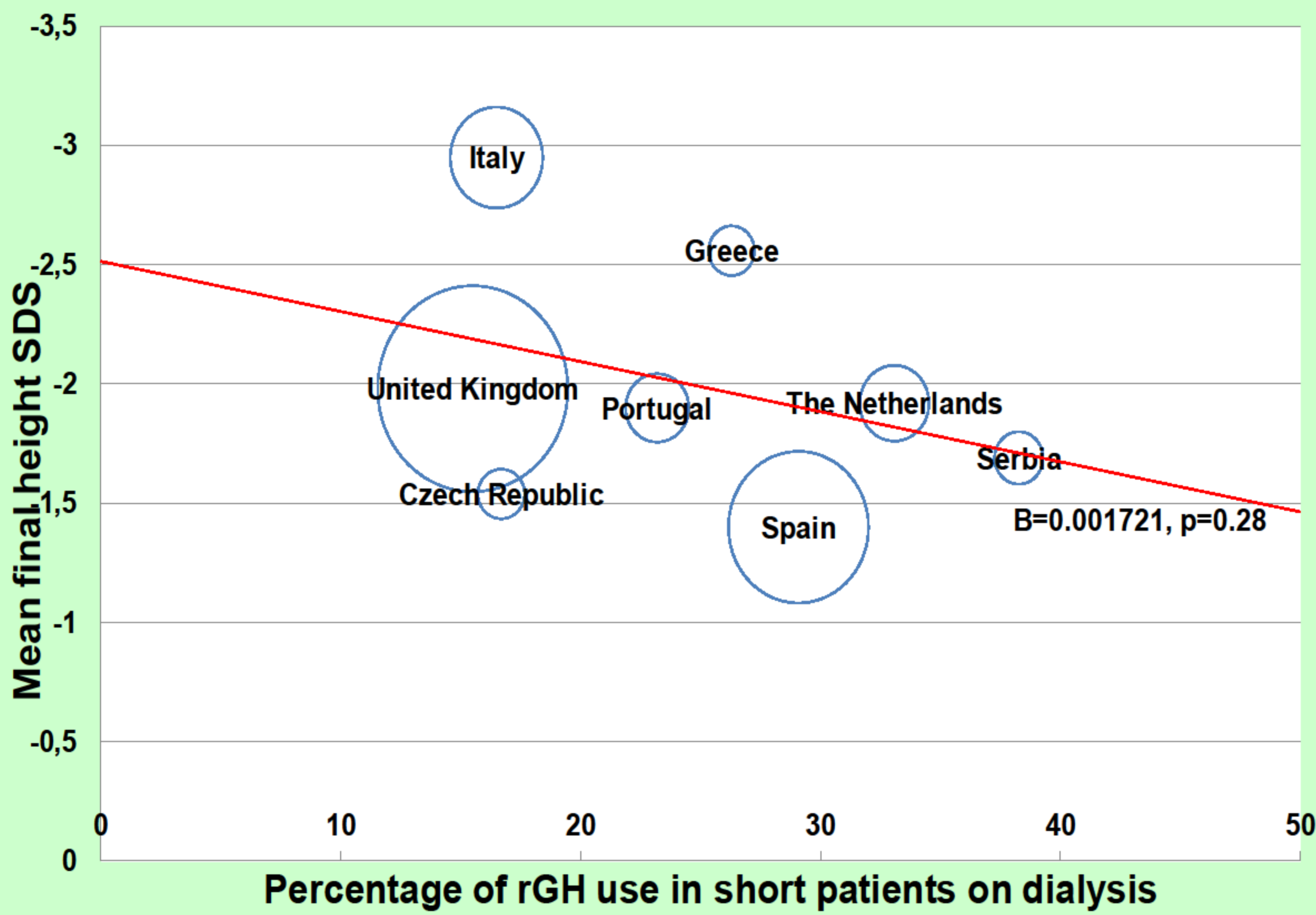
### Background

Growth retardation is a potentially treatable complication of paediatric end-stage renal disease and affects health related quality of life. We aimed to quantify the variation in growth hormone (rGH) policies and to compare policies with actual rGH use.

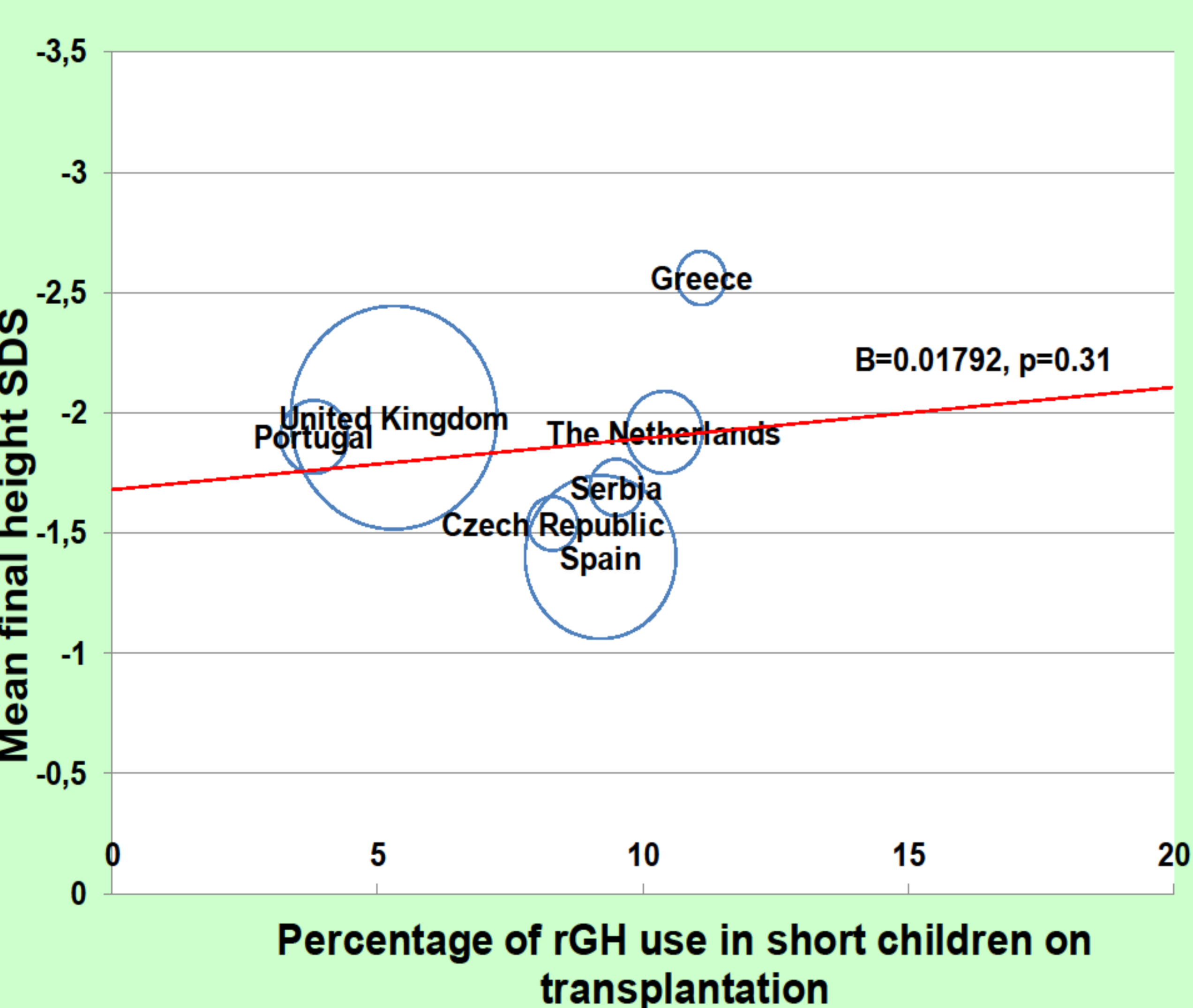
### Results

- rGH is reimbursed in 22 / 28 countries (78%).
- Mean height SDS was significantly higher when rGH was reimbursed -1.80 vs when it was not reimbursed (-2.35 (95%CI -2.49; -2.21),  $p < 0.001$ ).
- Minimum age (range 0-60 months) and the maximum age (range 14 to no limit) varied extensively

#### Actual rGH use and final height SDS in short dialysis patients



#### Actual rGH use and final height SDS in short Tx patients



### Methods

A questionnaire was sent to renal registry representatives or paediatric nephrology society correspondents of 38 countries in the European region. Data on height and actual use of rGH from 2007 onwards were retrieved from the ESPN/ERA-EDTA registry and the percentage of patients using rGH was calculated. Short stature was defined as: height standard deviation score (SDS) < -2.

#### Policies and outcome parameters

	Mean height SDS <sup>4</sup>	Mean height SDS <sup>4</sup> at start of RRT <sup>5</sup>	Mean final height SDS <sup>4</sup>
<b>rGH<sup>1</sup> prescription</b>			
No	-2.35 (-2.49; -2.21) <sup>7</sup>	-2.12 (-2.39; -1.84) <sup>7</sup>	-2.75 (-3.28; -2.20) <sup>7</sup>
<b>CKD<sup>2</sup> and dialysis</b>	-1.80 (-2.31; -1.24)	-1.80 (-2.53; -1.07)	-2.08 (-3.26; -0.89)
CKD <sup>2</sup> dialysis, Tx <sup>0</sup>	-1.80 (-2.04; -1.57)	-1.61 (-2.06; -1.15)	-1.77 (-2.22; -1.32)
<b>Minimum age rGH<sup>1</sup> prescription<sup>#</sup></b>			
0 < 12 months	-1.98 (-2.08; -1.88) <sup>7</sup>	-1.92 (-2.09; -1.75) <sup>7</sup>	-2.13 (-2.34; -1.91) <sup>7</sup>
12 ≤ months < 24	-1.88 (-2.08; -1.69) <sup>7</sup>	-1.21 (-1.54; -0.89)	-2.11 (-2.62; -1.59) <sup>7</sup>
≥ 24 months <sup>0</sup>	-1.54 (-1.79; -1.29)	-1.31 (-1.85; -0.77)	-1.51 (-1.95; -1.06)
<b>Maximum age rGH<sup>1</sup> prescription<sup>#</sup></b>			
< 18 years <sup>0</sup>			-1.40 (-1.84; -0.96)
≥ 18 years			-2.04 (-2.28; -1.80) <sup>7</sup>
<b>rGH<sup>1</sup> prescription in CKD<sup>2</sup> stages<sup>#</sup></b>			
CKD <sup>2</sup> stage IV-V	-1.78 (-2.00; -1.55)	-1.48 (-1.85; -1.10) <sup>7</sup>	-1.68 (-2.06; -1.31)
CKD <sup>2</sup> stage III-V	-1.55 (-1.66; -1.45) <sup>7</sup>	-1.32 (-1.51; -1.14) <sup>7</sup>	-1.50 (-1.73; -1.27) <sup>7</sup>
CKD <sup>2</sup> stage II-V	-2.16 (-2.34; -1.99) <sup>7</sup>	-1.64 (-1.95; -1.34)	-2.95 (-3.37; -2.52) <sup>7</sup>
CKD <sup>2</sup> stage I-V <sup>0</sup>	-1.80 (-2.26; -1.70)	-1.93 (-2.58; -1.29)	-1.95 (-2.50; -1.39)
<b>Height criteria for rGH<sup>1</sup> prescription<sup>#</sup></b>			
Height SDS <sup>4</sup> /or growth velocity <sup>0</sup>	-1.79 (-2.03; -1.54)	-1.75 (-2.29; -1.21)	-1.66 (-2.11; -1.23)
Height SDS <sup>4</sup>	-1.87 (-2.13 -1.60)	-0.90 (-1.32; -0.49) <sup>6,7</sup>	-2.35 (-3.07; -1.63)
Height SDS <sup>4</sup> and growth velocity	-1.88 (-2.00; -1.76)	-1.34 (-1.55; -1.13) <sup>7</sup>	-2.10 (-2.36; -1.84) <sup>7</sup>
<b>Minimum duration of growth retardation #</b>			
< 12 months <sup>0</sup>	-1.81 (-2.08; -1.54)	-1.64 (-2.29; -0.98)	-1.79 (-2.34; -1.24)
≥ 12 months	-1.81 (-1.94; -1.68)	-1.38 (-1.63; -1.12) <sup>7</sup>	-1.75 (-2.03; -1.48)

0 reference group  
1 growth hormone  
2 chronic kidney disease

3 transplantation  
4 standard deviation score  
5 renal replacement therapy

6 only data of Bulgaria and Greece  
7 significant difference from reference group

### Conclusions

There is considerable variation in rGH policies across Europe, which affects (final) height. In addition, not all patients that would be considered eligible according to their national policy, are receiving rGH. Therefore, differences in short stature in paediatric ESRD patients across Europe may be not only explained by differences in access to growth hormone therapy, but also by doctors' and patient's' attitudes towards rGH therapy.

WE WOULD LIKE TO THANK ALL FOR CONTRIBUTING TO THE ESPN/ERA-EDTA REGISTRY

