

# IMPLEMENTATION OF A GROWTH DISORDERS RELATED TWINNING PROGRAM IN PEDIATRIC ENDOCRINOLOGY – IS IT NECESSARY AND FEASIBLE?

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## BACKGROUND

Until March 2019 only two centers for diagnosis and treatment of growth disorders are operating in the Western and Eastern parts of Bulgaria. About 200 children are currently Growth Hormone (GH) treated while at least as many children with growth disorders from mostly Central Northern and Southern Bulgaria are presumably not diagnosed. A national partnership program (Partners4Growth) was developed and is about to start.

National Health Insurance Fund in Bulgaria reimburses treatment with GH for children with growth hormone deficiency (GHD), Turner syndrome (TS), Prader-Willi syndrome (PWS) and chronic renal failure. Charity funds are responsible for treating SGA children without postnatal catch up growth, children with Silver-Russell and Noonan syndrome.

Furthermore, there is no nationality accepted algorithm for the diagnosis and treatment of short stature across the country.

## OBJECTIVES

To create, organize and introduce in the clinical practice a program for diagnosis and treatment of children with conditions related to GH deficiency from Central Northern Bulgaria in active collaboration with an established center - Varna Expert Center of Endocrine Diseases (VECREd), acting as a pilot for Partners4Growth.

## MATERIAL AND METHODS

### Elaborating a structured program

- Assessment of available resources (infrastructure) – human resources, functional/examination room, wall-mounted stadiometer, weight scale, centrifuge, laboratory, radiographic and imaging diagnostics, hospital support, financing
- An analysis of the current organization for diagnosis and treatment with GH
- Assessment of barriers and facilitators

### Testing the program in real conditions

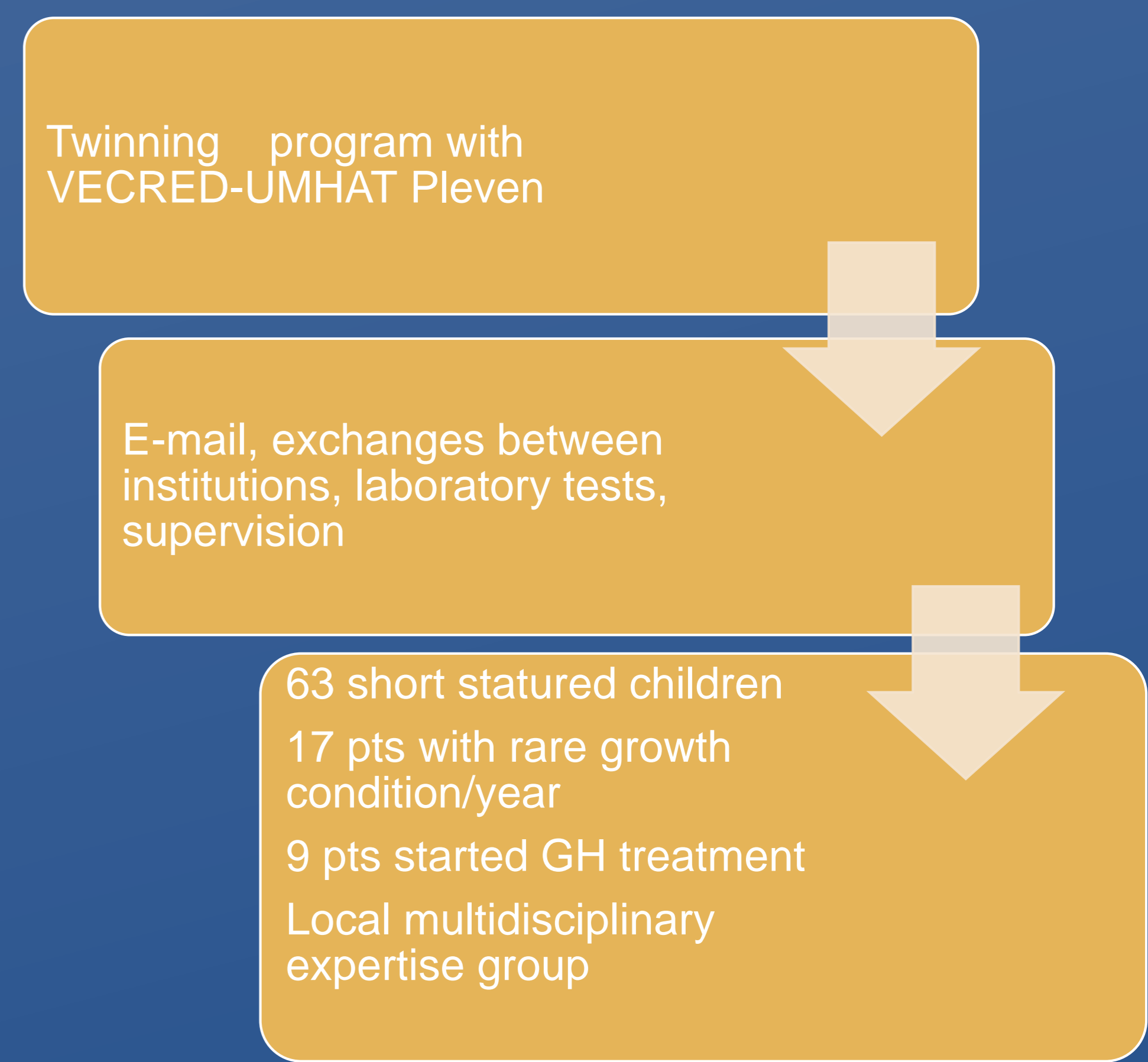
- Twinning started with e-mail communication and exchanges between institutions
- Preliminary discussion of cases with the established center was performed.
- Introduction of standardized auxology, assessment of growth according to percentile position, midparental height, individual growth curves
- Initial screening laboratory tests
- Grouping children with GH deficiency
- Exchange knowledge and experience during diagnostic and treatment of children with growth disorders

### Working with patients at UMHAT Pleven on site

- First patients' evaluation and GH stimulation tests on place, under supervision of a group from VECREd
- Part of the laboratory tests were performed at VECREd initially and locally after the end of the first year
- Started treatment with GH and following-up the effect of therapy (self-starting GH therapy and education/supervision of patients)
- Building teams of healthcare professionals in Plevan trained to work with children with growth deviations, assuring sustainability of the program
- A local multidisciplinary expertise group for GH treatment was established in Plevan and began work in June 2019

## RESULTS

- Start of the twinning program in Plevan region (49,917 children) in March 2018, active supervision from the VECREd
- 63 short statured children who visited outpatient clinics were screened for one year
- 17 (26.9%) were diagnosed with rare growth condition, 9 of them (52.9%) started GH treatment (55.6% male; 6 with GH deficiency, 2 with PWS, 1 with Turner syndrome)
- Average age at the start of GH therapy of  $9.58 \pm 3.7$  years
- Average growth velocity of  $10.24 \pm 4.0$  cm/year



## Study groups

IGHD - 4 patients (6.3%) and MPHD - 2 patients (3.1%)

Ad observation for GHD - 7 patients (11.1%)

Syndromic short stature - 15 patients (23.8%): Turner syndrome - 2 pts (3.1%), Prader-Willi syndrome - 2 pts (3.1%), Noonan syndrome - 1 pt (1.58%), Cornelia de Lange syndrome - 1 pt (1.58%), PHP 1a - 1 pt (1.58%), ring 15 chromosome - 1 pt (1.58%), Down syndrome - 7 pts (11.1%)

SGA without postnatal catch-up - 6 children (9.5%)  
Prematurely born - 5 children (7.9%)

Familial short stature and constitutional growth and puberty delay - 20 pts (31.7%)

Iatrogenic short stature (Muscle dystrophy) - 1 pt  
Anorexia - 1 pt (1.58%)

Crohn disease - 1 pt (1.58%)

Celiac disease - 1 pt (1.58%)

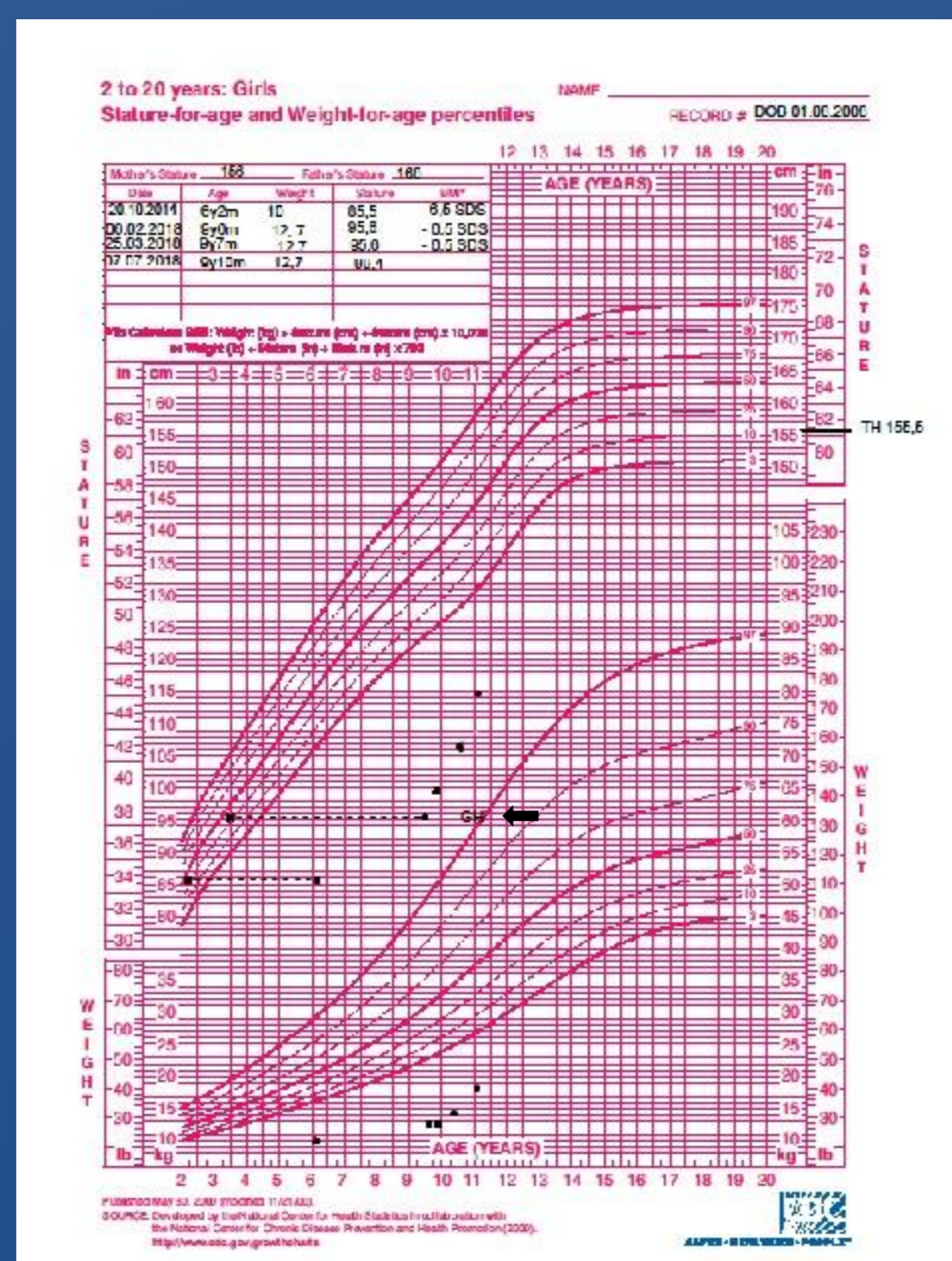


Fig.1 Girl, aged 11 with MPHD

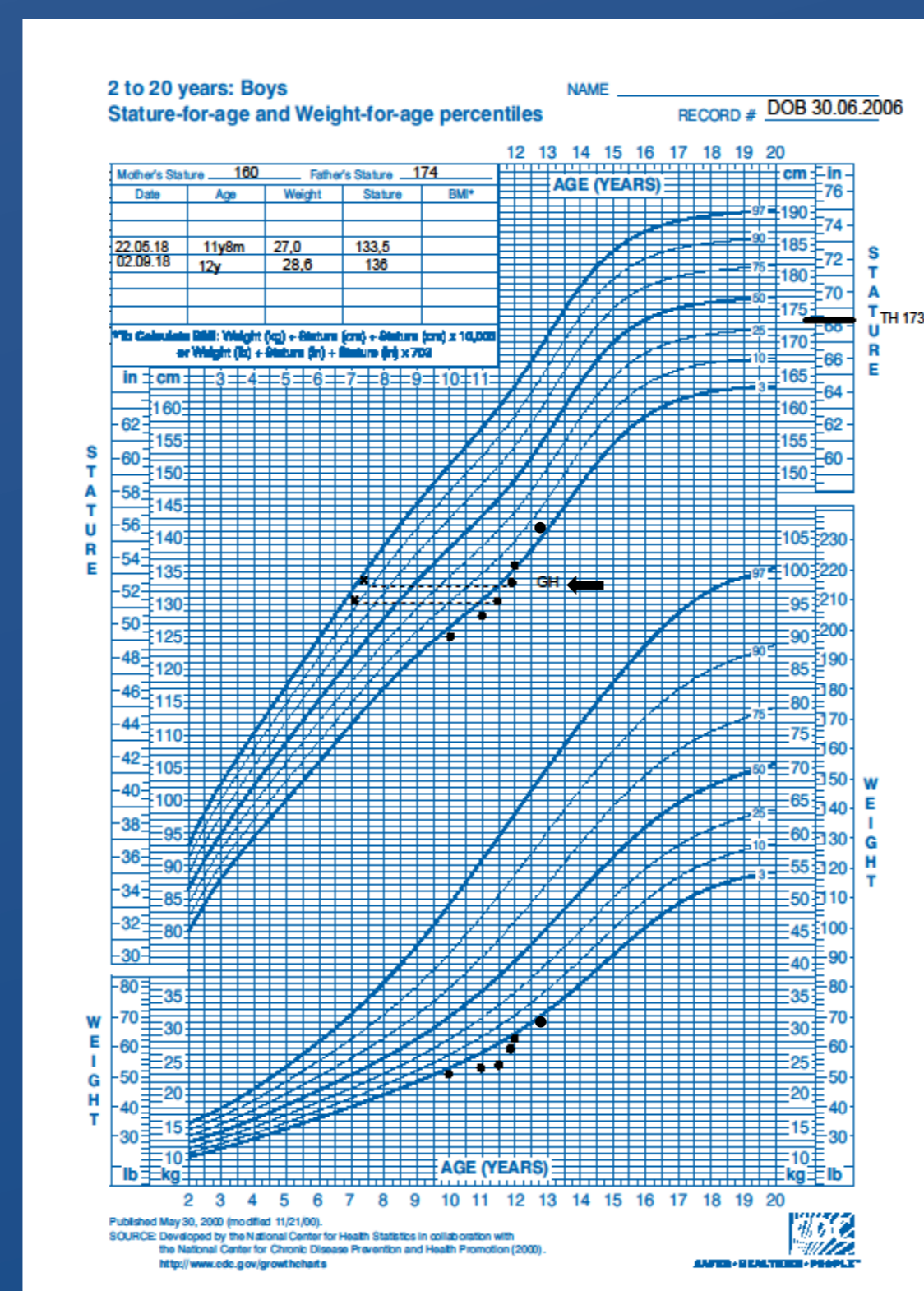


Fig.2 Boy, aged 12 with IGHD

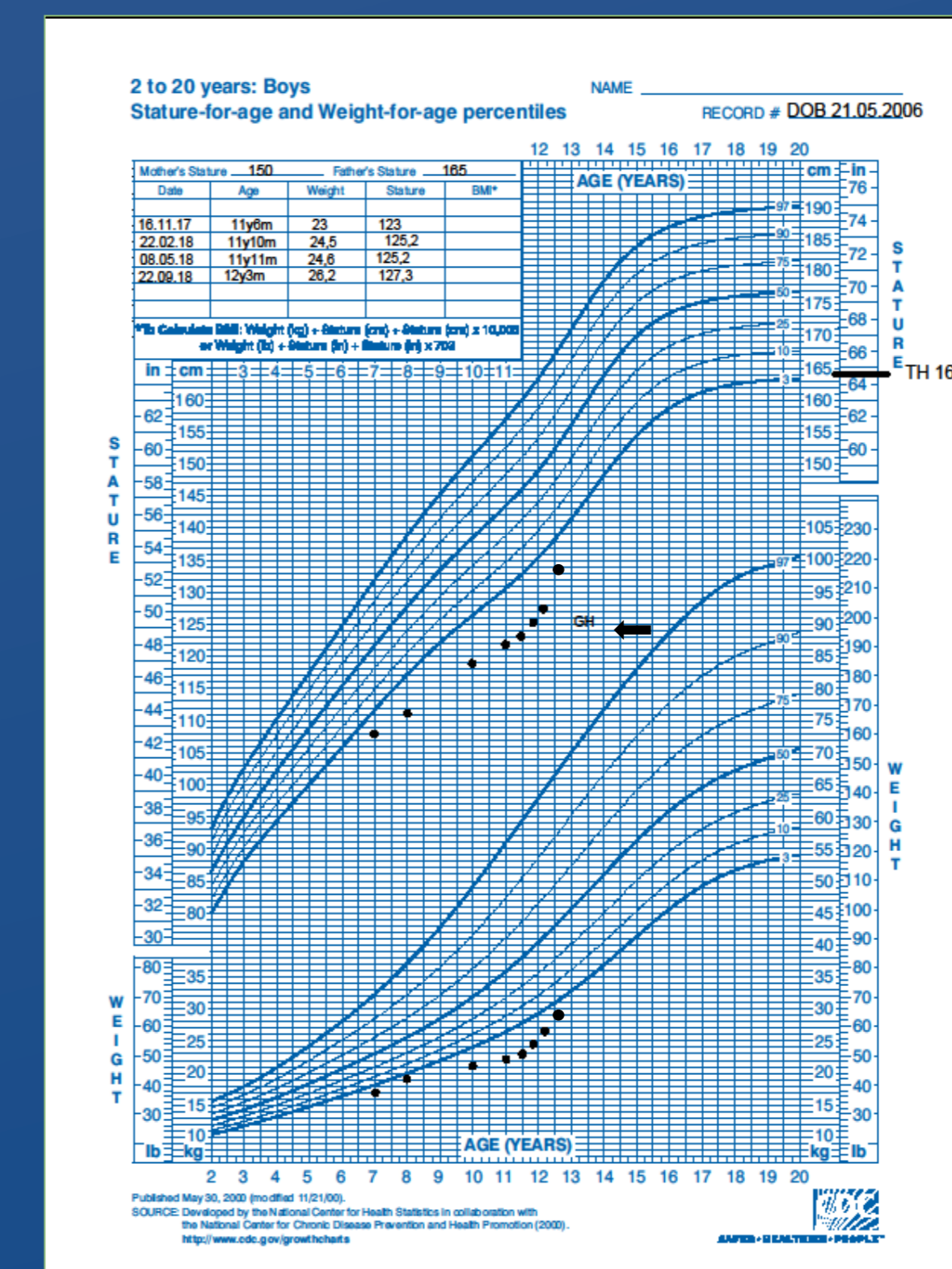


Fig.3 Boy, aged 12 with IGHD

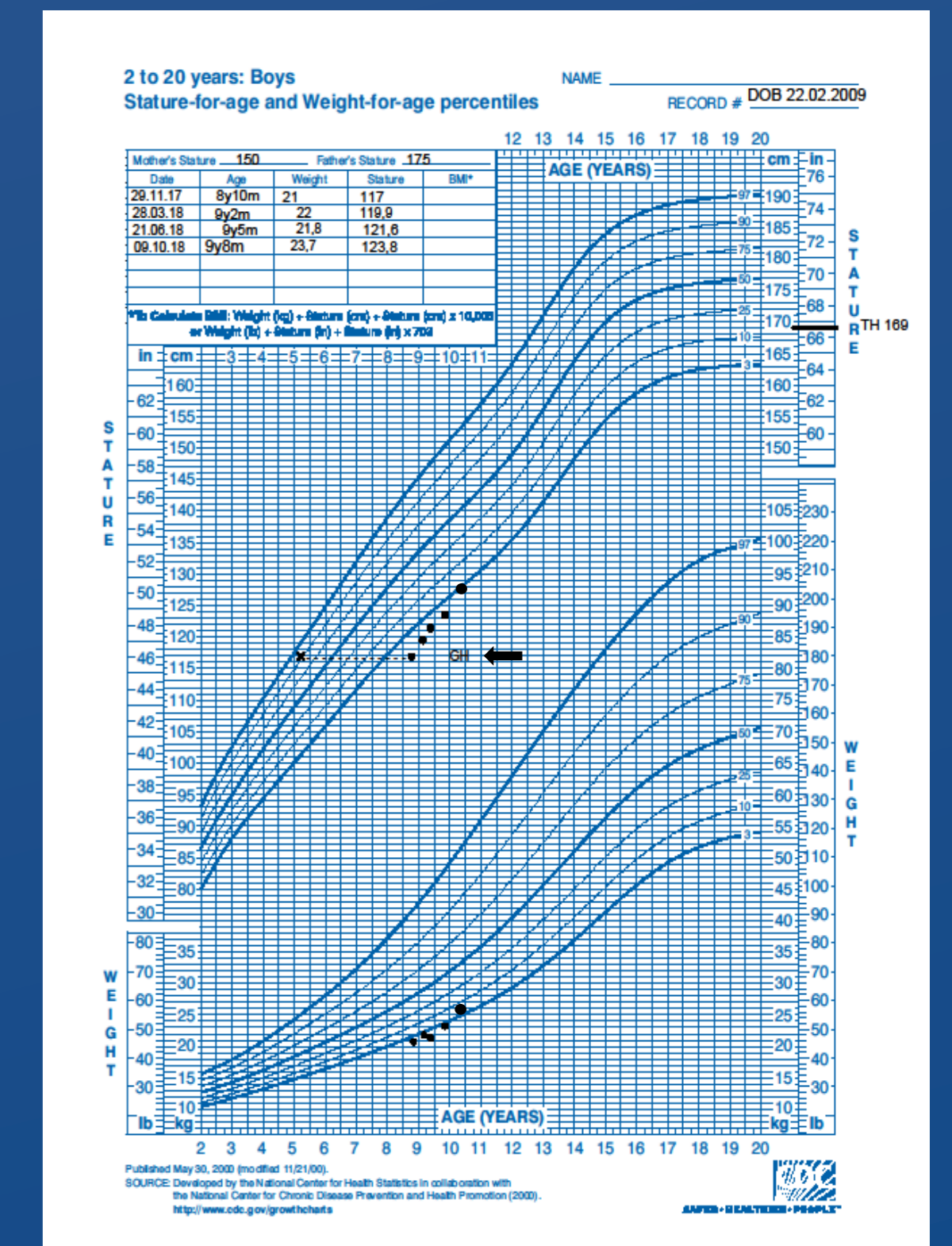


Fig.4 Boy, aged 9 with IGHD

## CONCLUSION:

The twinning enabled the quick training in initial work-up, start of GH treatment and follow up of patients of the local team. Possibilities for successful diagnosis and treatment of growth disorders on place were created within one calendar year. The next steps aim to create local multidisciplinary team expertise, acquire more experience and self-confidence while still communicating with the supervisors and thus, improve quality of care.