

“Resource allocation for the GUCH*-patients, why is it necessary?”

The GUCH population is growing dramatically. Expectancy for CHD* children to reach adulthood is nowadays 95% vs. 65% in the seventies. This is due to the significant increase for “simple” CHD, whereas the survival rate for complex CHD is constant since 1985 (Canadian study from Quebec, Marelli et al. in Circulation, 2007, 115:163-172).

The mortality curves per age-group were bimodal in 1985 and more normal distributed in 2000.

In 2018 in 18 selected European countries there will be 1.067.000 GUCHES, among them 111.400 with complex CHD.

Transition from paediatric to adult cardiology shows a gap at the age of 18 to about 25 years. Transition should be characterized by growing knowledge of the patients themselves. There has to be a multidisciplinary approach. There are different levels of care for the GUCHES: tertiary, regional hospital and GUCH-centres.

In our countries in 2018 there will be
GUCH population 1 Million people (1.067.700)

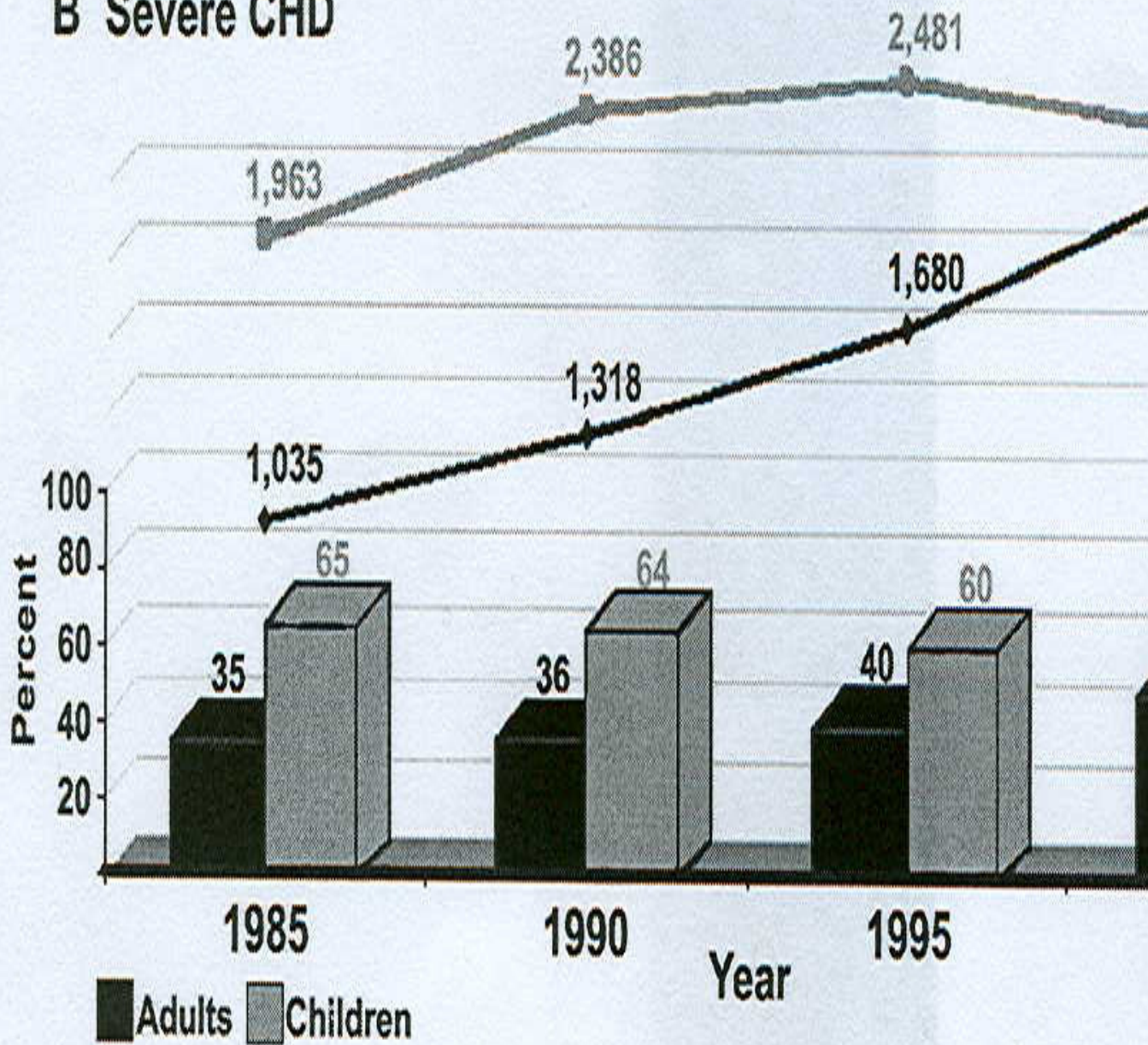
Complex GUCH	111.400	111.400
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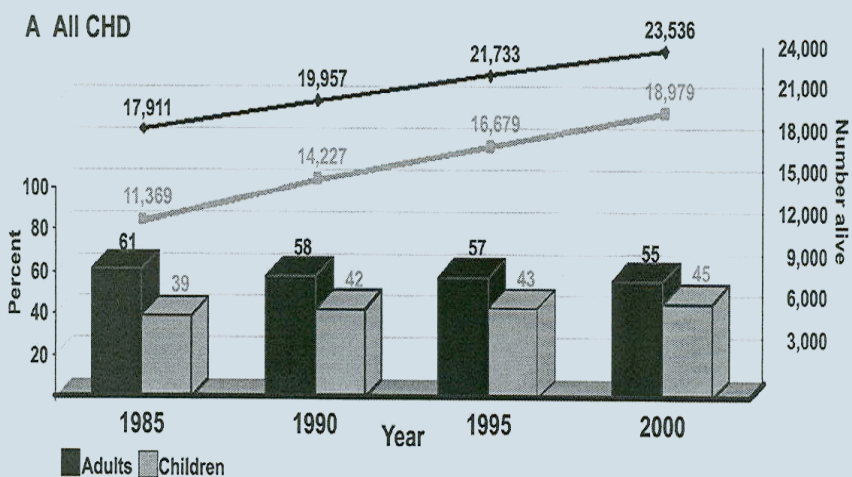
<u>GUCHComplex</u>		<u>GUCH</u>
Romania	75.400	7.000
Sweden	32.300	3.000
Polen	136.400	12.700
Norway	18.000	1.700
Austria	28.700	2.700
Finland	18.000	1.700
Irland	14.400	1.400
Denmark	18.000	1.700
Germany	288.000	26.700
Iceland	1.100	100
Great Br	215.000	20.000
Belgium	34.000	3.500
Spain	144.000	13.300
Bulgaria	31.000	2.800
Portugal	34.000	3.500
Estonia	5.500	500
Greece	39.500	3.700
Netherlands	57.400	5.400

Discussion: The education-program for “GUCHologists” is still in a status of development. Many of the GUCHES are at risk not to be treated adequately. Although there are only little numbers of GUCHES in smaller countries the problems are the same. A good follow-up seems essential to ensure the efficiency of the medical treatment.

A sensitisation of politicians is necessary. It would make sense to go to the health ministries with guidelines and to ask for their priorities.

B Severe CHD





*CHD = Congenital heart disease

* GUCH=Grown ups with congenital heart disease

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