# *Role of the Hungarian Congenital Abnormality Registry in prevention of birth defects*

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# *THE IMPORTANCE OF CONGENITAL ANOMAILES IN PUBLIC HEALTH*

**~ can be based on the prevalence and number of affected cases and the seriousness of health status**

- In Hungary cogenital anomalies (CAs') calculated prevalence is ~*6%*.
- In Hungary, CAs are among the top 10 major causes of mortality and the second major cause of infant mortality. (20-25% of prenatal mortality)
- Pregnancies with CA end up more frequently with abortion, miscarrieage or still-birth
- In case of surviving fetus and babies there is higher probability of grow disorders and adaptational disfunctions.
- In case of CAs complete recovery is rare for major defects, and they raise many individual/social and physical/psychological problems, therefore the optimal solution is prevention.

# *HUNGARIAN CONGENITAL ABNORMALITIES REGISTRY I.*

History:

1962 - Start of the notification of contagiosus diseases and CAs in Hungary.

1970- Creating the National Surveillance of Congenital Abnormalities (NSCA), which manages the Hungarian Congenital Abnormality Registry (HCAR)

1973 - International co-operation begins

1974 - Start of CA monitoring (periodical and geographical cluster analysis)

1980 - Start of the CA etiological monitoring: Hungarian Congenital Case-Control Surveillance.

Based on obligatory notification of CA cases by diagnosing medical doctors:

→Pediatric, Obstetric, Pathological Institutions and Prenatal Centers

***The database covers the full Hungarian population (approximately 100.000 births annually)***

# *HUNGARIAN CONGENITAL ABNORMALITIES REGISTRY II.*

**AIMS**

- To assess the number and frequency of each CA
- To help to establish the number of handicapped persons (important for social and medical-health planning)
- To promote primary and secondary prevention
- To provide materials for scientific research and
- To enable international co-operation

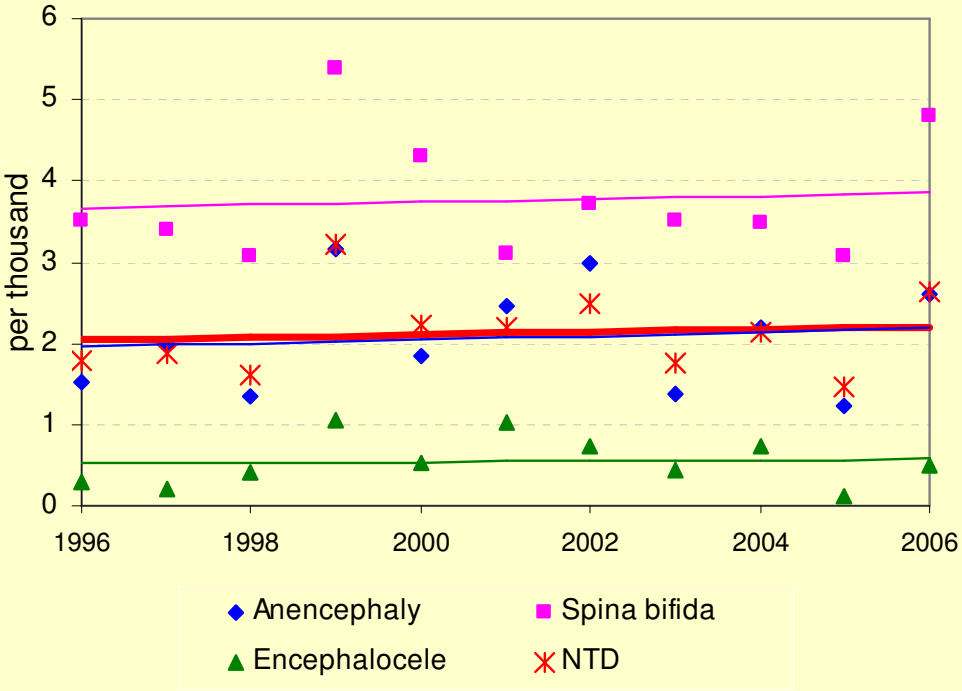
**TASKS**

- The HCAR continually collects, records, keeps and analyses the personal and health data of cases with CA from the birth till the age of one year (including the prenatally diagnosed and terminated malformed fetuses (from 1984 onwards)
- Provides regular statistical evaluations (quarterly and yearly)
- Analyzes the geographical distribution and time-trend for some selected CAs.

***The results of the HCAR's analysis on the prevalence of two CAs: NTD and CLP - which were in the focus of the past couple of years - are hereby presented.***

# *Time-trend analysis of neural tube defects*

- Neural tube defects (NTDs) are among the most frequent congenital anomalies.
- Considering their etiology it has multifactorial origin: caused by gene-environmental interaction when the so-called polygenic predisposition is triggered by environmental 'risk' factors.
- NTDs are serious birth defects with symptoms that range from mild to severe impairment.

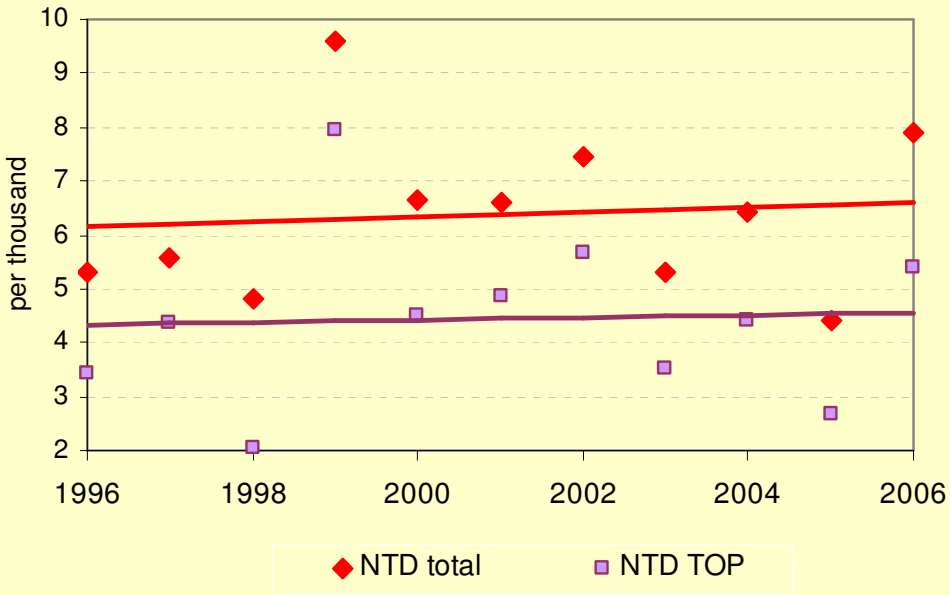



***Prevalence of neural tube defects (NTDs) between 1996-2006***

# *Time-trend analysis of neural tube defects II.*

- Analyzing the prevalence of NTDs and the effectiveness of prenatal diagnosis in detecting NTDs both curves show a slightly increasing trend but there is no significant improvement in the past examined years.

- Increasing prevalence might be due to the more effective notification.




***Prevalence of cases with neural tube defects (NTDs) and prenatally detected cases with NTDs between 1996-2006***

# *The results of HCAR research on NTDs*

- ***In a previous HCAR study***, mothers were interviewed on their knowledge related to the folic acid:

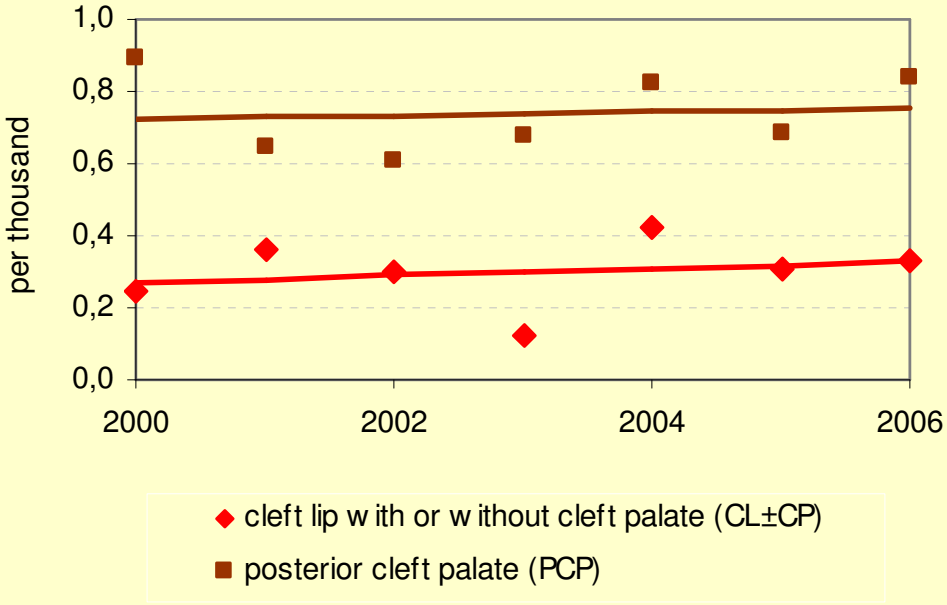
A. The majority of mothers interviewed used folic acid supplementation during pregnancy.

B. Although more than two-third of the surveyed participants reported that their pregnancy had been planned, only few (9%) of them started the supplementation before the conception.

- **This improper method of folic acid consumption could be one of the reason for the non-decreasing total prevalence of NTDs.**

# *Time-trend analysis of orofacial clefts I.*

- Considering the prevalence of isolated cleft lip with or without cleft palate (CL±CP) and posterior cleft palate (PCP) during the past seven years (from the year of 2000) there is a slightly increasing tendency in the case of both anomalies on the database of HCAR.



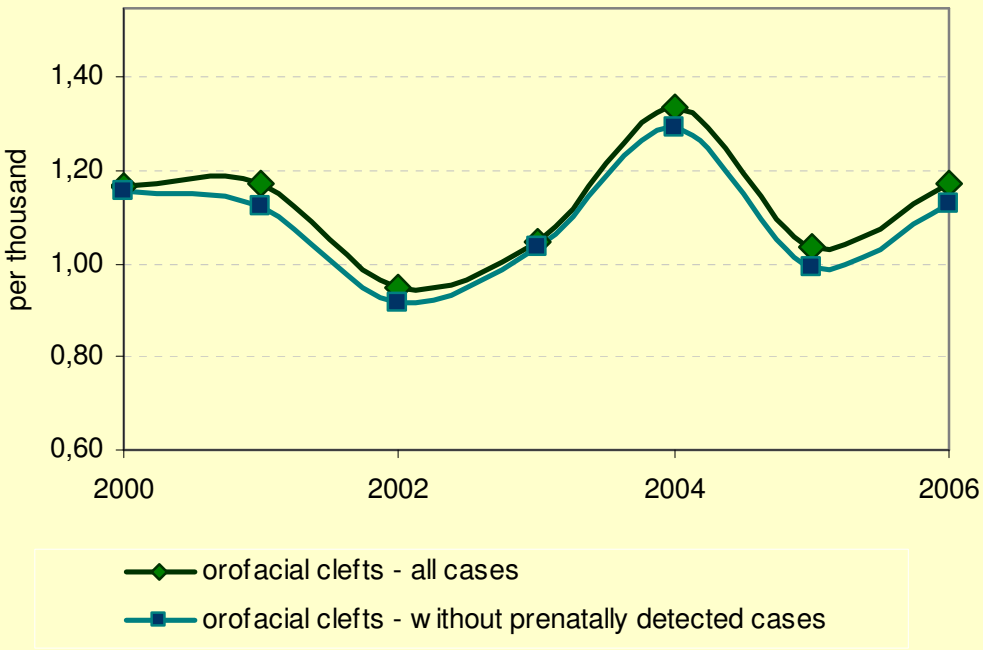

***Prevalence per thousand of cleft lip with or without cleft palate and posterior cleft palate between 2000-2006 on the database of HCAR***

# *Time-trend analysis of orofacial clefts II.*

- Analyzing the total prevalence of orofacial clefts and prevalence of all orofacial clefts without prenatally detected cases it is noticeable, that the two curves almost cover each other in the examined years.

- The difference between the two curves shows that the prenatal detection of cases with OFC was very low in each year (3-5 cases per year).

- The number of prenatally diagnosed OFC cases in Hungary is low. The HCAR tries to assess the possible causes of OFCs to help primary prevention.




***Prevalence of all orofacial clefts (all cases of CL±CP and PCP), and prevalence of cases with OFC without prenatally detected cases between 2000-2006 on the database of HCAR***

# *The results of HCAR research on orofacial clefts*

- The HCAR's epidemiological study revealed that periconceptional use of multivitamin+FA supplementation is able to decrease the risk for orofacial cleft.
- Therefore the use of periconceptional supplementation (containing folic acid) would be recommended.
- Besides an HCAR study found that some maternal diseases with fever act as risk factors for the pathogenesis of isolated CL±CP and PCP. Thus the teratogenetic effect of acute maternal diseases with fever can be limited by preventive (e.g. vaccination against influenza) or early and adequate antifever treatment.
- An increased risk for isolated CL±CP and PCP was found in cases born to mothers with **influenza, common cold, orofacial herpes** and **gastroenteritis** and for isolated posterior cleft palate in mothers with **influenza, sinusitis** and **bronchitis** during the critical prenatal period of these defects.
- Among chronic maternal diseases, **epilepsy** and **angina pectoris** showed a higher prevalence in the mothers of cases with isolated orofacial clefts.

Erzsébet Puhó, Melinda Szunyogh, Andrew E. Czeizel, Julia Métneki.: Maternal diseases and isolated orofacial clefts in Hungary. Birth Defects Research,. Part A Clin. Mol. Teratol. 2005. 73 (9) 617-623.

# *Conclusion*

The HCAR provides a centralized surveillance, and can play a significant role in monitoring and supporting prevention efforts of CAs in Hungary but more resources are needed to expand its activities.

- Some major CAs (including NTDs and OFCs) could be prevented by periconceptional folic acid/multivitamin supplementation.
- Although folic acid supplementation has been recommended in Hungary since the early 1990s, it does not seem to influence the prevalence of NTDs and OFCs due to the improper use of supplementation.
- Increased effectivity of primary prevention could be beneficial both for individuals and the society.
- Practical realization and working out of the method of primary prevention is an actual national and public health care task in Hungary.

Thank you
for your attention!