



Kind & Gezin

# ALGO<sup>®</sup> HEARING SCREENING

REPORT FOR 2000

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ANNUAL RESULTS FROM FLANDERS

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## SUMMARY AND CONCLUSIONS

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# FOREWORD

Starting in 1998 Kind & Gezin (Child and Family) offers Universal Early Hearing Screening to all newborns living in the Flemish Region of Belgium and also in the Brussels Capital Region. The preferred method is a further development of Auditory Brainstem Response Audiometry– well known as ABR the scientifically accepted Golden Standard for diagnosis of hearing impairment. The approach allows ascertaining hearing impairment even before the second month of life. The combination of early detection, integrated early rehabilitation and home guidance services is of optimal benefit for the development opportunities of babies with hearing impairment. The program offers these babies the best opportunity to fully develop oral communication patterns ensuring them to integrate successfully in their hearing society. Often starting before the third month of life, the rehabilitation program and early home guidance service appeals to babies' most flexible neural developmental stage of life. Results are astonishing, Centres for Education of Deaf Children report no hearing impaired children have been admitted anymore since the implementation of Kind & Gezin's Universal Early Hearing Screening project in Flanders. Quality controlled audit confirmed this remarkable result. Isn't this the ultimate aim of evidence based preventive programs

Some congenital hearing disorders are still not detectable in the first life stage but will show up later. Progressive hearing disorders, late onset hearing impairment and fluctuating hearing problems can be the reason of a delayed detection. It is only for some time we are getting aware of this reality. It is a contribution of universal hearing screening programs and sustained follow-up of language and speech development in babies and toddlers this came to our awareness. Hearing impairment caused by trauma or severe childhood infections are also early detected. In 2000 Kind & Gezin implemented in all districts an instrument most suited for measuring massive and single neuromotor development. This Van Wiecheninstrument is also appropriate for the evaluation of the development of oral communication skills. This creates the ability to detect in an early stage late onset hearing impairment in children who comes to the Baby Welfare Clinics of Kind & Gezin. As all services provided by Kind & Gezin this follow-up program is free ensuring an important health increasing effect for all babies..

Flanders still is one of the world largest geographical area systematically offering an early hearing-screening program to all babies. It is fully compliant to the recommendations of the Joint Committee on Infant Hearing 1994 Position Statement (American Academy of Paediatrics 1994) and de European Consensus Statement on Neonatal Hearing Screening 2000 (Milan 2000). In the US 17 states legislation has been passed in favour of universal newborn hearing screening protocols and started already with screening programs. The United Kingdom plans the introduction of universal hearing screening for 2004. Scotland will be ahead of the UK with a program starting up in 2003. Also the Netherlands are expected to implement a universal program in 2003 which will be nationwide available in 2007. The French speaking part of Belgium hasn't drawn the outlines yet for screening for hearing impairment, neither do Germany of France.

Our country neighbours are doing their best to listen to the needs of their babies being well aware each delay in the introduction of a universal hearing screening program will put a high cost on the developmental opportunities of the not early detected babies with permanent childhood hearing impairment.

Both the in-house databank management software (IKAROS) and Kind & Gezin's own ICT department played an essential role in the collection and processing of the mass of data. The databank entries were regularly tested for accuracy and consistency. Those carrying out the tests were made responsible for data entries and were authorised, among other things, to amend or correct the data they had keyed in.

This report contains the results of the third year of universal early hearing screening in Flanders. It is both a management report and a research report. The first part describes the organisational aspects, which were taken on board in 2000. The second part contains the figures from the screening and referral details relating to babies born in 2000. The third part contains the obtained results for each province as well as for the Brussels Capital Region.

An extended list of references is also included in this report.

A special word of thanks is due to our IKAROS-expert, Mrs. Ingrid Testelmans, and the ICT team, who made a substantial contribution to the realisation of this report.

We should also like to thank the members of the Scientific Advisory Body for Hearing Screening and the experts who contributed to this report, in particular Prof. Dr. Christian Desloovere and Prof. Dr. Paul Van de Heyning.

# INTRODUCTION

## *Organisation of universal early hearing screening in Flanders using Automated Brainstem Audiometry*

### **Early hearing screening**

Permanent Childhood Hearing Impairment (PCHI) affects 1-1.4 per thousand new-borns. The number of births in the Flemish Region was 63.042 in 1998, 61.906 in 1999 and 61.877 in 2000. This means this region should expect annually 65 babies suffering from a severe hearing impairment. Neonatal Intensive Care graduates are even known to run a 10 to 15 times higher risk for hearing disorders. A study run in the Netherlands on 2513 NICU graduates showed prevalence of 1.9 % congenital bilateral hearing impairment and 0.6% congenital unilateral hearing impairment. (Van Straaten HLM June 2001). Children with an auditory disability are deprived of the sensory input, which is essential for the development of speech. Furthermore, the disability has a pernicious effect on the total development of the social, emotional, comprehension and motor aspects of the personality and the process of education and parent/child interaction. (Joint Committee on Infant Hearing 1994 Position Statement).

Research has given evidence for the significantly higher level of receptive and expressive language abilities when auditive stimulation of the cerebral cortex could start before 6 months of age compared with children who do not receive a hearing aid until the age of 7 to 18 months (Yoshinaga 1998).

Until 1997, systematic testing for hearing problems in the Flemish Region was carried out using the Ewing distraction test at 9 months. It was not generally possible to begin rehabilitation until after the age of 7 to 18 months, which is far too late. Since 1997 hearing disorders have been detected by automated brainstem audiometry at the age of four weeks.

The Joint Committee on Infant Hearing (JCIH) and the American Academy of Paediatrics (AAP) have as their aim the universal screening for hearing impairment in babies. The "Position Statement 2000" was added to this report as attachment #3. This recommendation has been confirmed by European authorities in the European Consensus Statement 2000 (Milan, 2000).

Flanders, including the Brussels Capital Region, was the first region in the world to introduce a universal hearing-screening programme for the whole population. Between March 1997 and March 2000, more than 200,000 healthy babies were screened for hearing defects by the district nurses from Kind & Gezin (K&G) using automated auditory brainstem response tests.

## **When to perform a hearing screening?**

Confronted with a ever decreasing hospitalisation period for deliveries, a important turnover of staff, a high workload, laborious follow-up and a increasing amount of policlinic and home deliveries make neonatal hearing screening prior to discharge a hell of a job.

Optimising target group cover prior to the discharge is hard to achieve, as shown in some foreign studies (White, K.R. 2000).

Pushing the screening to the earliest possible moment after birth will increase the amount of babies to be retested, stressing parents and personnel. Recent publications show a increase of specificity and decrease of false positive results for those test carried out later. (Sokol. J, Hyde M, 2002, White, K. R., 2000, Vohr, B.R. Oh, W. et al., 2001). “False alarms” will shake confidence in parents and professional healthcare takers, which will influence the trigger effect of the screening.

From a pedagogical point of view several reasons can be given to postpone a hearing screening. First weeks of life are most crucial for the identification process of parents and their baby. Any concern regarding a congenital anomalies or ascertainment of disorders following referral can harm the brand new relationship between parents and child. Parents experience a certain loss which can badly affect parental bonding or by pedagogues commonly named “attachment”

In the first weeks after birth, medical models can't give any relief when a hearing disorder has been ascertained. Rehabilitation programs will only be started from the 2<sup>nd</sup> or 3<sup>rd</sup> month of live on and thus don't force for having a hearing screening performed short after birth.

Parents will also be focussed on their babies lost abilities and presumably won't consider the all left developmental abilities and communication needs for their baby. Communication isn't a evidence from now on; in addition the level of joy parents experience in the spontaneous relationship with their babies will decrease. As a result parents will decrease their gazing at their baby while communicating. (Lichtert, G.1993; Broesterhuizen, M., 2001)

Theoretically it seems most appropriate to screen babies prior to dismissal. Therefore and additionally having to chase and trace babies after discharge most countries considering a nationwide screening program. Question is if this approach does not has a high relational cost.

Kind en Gezin covers all newborns with its prevention care program and has chosen to offer a free ALGO<sup>®</sup> hearing screening 4 or 6 weeks after birth, which allows Kind en Gezin to fully integrate this screening in the standard schedule of care. Parents with a first child are the test offered at age of approximately 4 weeks; parents with a second or following child will have testing planned at the age of 6 weeks.

To be successful a program targeting at prevention of hearing disorders has to be watched on a governmental level, being part of a project of nationwide health care.

Protocolled screening is just one part of this, just a first step. Universal screening, a swift retest procedure for those who failed for the first testing and a controlled referral to a highly qualified and experienced Centre of Excellence, offering accurate audiological assessment, early home intervention and integrated rehabilitation are as essential as performing screening tests itself.

As a result of close collaboration of all Flemish ENT university centres, prestigious centres of Excellence for hearing disorders and Kind en Gezin, this integrated umbrella model has seen the light.

## **The apparatus used.**

The Algo test is an objective hearing test directly derived from the traditional Auditory Brainstem Response test (ABR – also known as the BERA test). The ABR test is generally regarded as the “gold standard”, the reference test for evaluation of the hearing system. It is an application of the technique of electro-encephalography. When a tone is applied to the ear, the brain (brainstem) responds to this with electrical responses, which are measurable via electrodes on the skull. The signal obtained is compared with a reference signal (a template) from children with normal hearing. The detection algorithm employs binominal sampling: the statistical programme calculates the likelihood ratio (LR), the probability ratio, which states how much a response plus background noise differs from a pure noise or no –response condition. After 1,000 and not more than 15,000 clicks the apparatus shows a ‘pass’ result if there is 99.98% certainty of good hearing and a ‘refer’ if that certainty is not achieved.

The test is carried out by one person who does not require audiological training. The apparatus is portable, works on batteries and does not require a special test environment. Both ears are automatically tested one after the other (or separately if desired). The apparatus corrects for ambient noise and for myogenic interference. The simplicity in performing a hearing test is mirrored in the organisational structure of the Kind en Gezin organisation. This proves to be one of the core elements making this project very successful.

### **The organisation Kind & Gezin**

Kind & Gezin (Child & Family) is a Flemish public agency whose purpose is to promote welfare and health of all children up to the age of three years with special interests in their immediate living conditions. To this end all mothers who have just given birth are visited in the maternity ward and also receive three house calls from a nurse. K&G organise preventive consultations for babies in whom the children are examined, advice is given and vaccinations are carried out.

Further tasks are prenatal and perinatal preventive care, child-minding and out-of-school care initiatives, child abuse and neglect, children's rights, adoption and the care of children in particular living situations.

The screening of babies for hearing defects is one of K&G's tasks as laid down in a decree (Act of the Flemish Community of May 29, 1984).

For the implementation of preventive care, K&G has around 630 district nurses employed in 330 welfare baby clinics spread over 63 districts, each with a district centre. They function as self-regulating teams in co-operation with the welfare baby clinic medical officers, which means that each district evaluates the cover of its target group and among other things also determines autonomously which is for them the preferable location for hearing screening (e.g. at the district centre, during house calls, in Kind & Gezin's welfare baby clinic premises, in the preventive care centre (a more extended welfare baby clinic) in order to maximise target group cover.

The district nurses have contact with virtually all newborn babies via the bedside visit at the maternity ward, house calls or consultations in the welfare baby clinic. The K&G IKAROS database covers all newborn babies in Flanders.

### **The organisation of hearing screening in Flanders**

During the visit to the maternity ward every new mother is made aware of hearing screening. She is given extensive information and a folder about the ALGO<sup>D</sup> test, which explains how to ensure optimal test conditions (e.g. no oil bath just before the test). During the first home visit or preventive consultation, an appointment is made for the test.

At about the age of four weeks the district nurse carries out the hearing screening. This is fully integrated into the normal programme of basic preventive care, so that no additional time or additional staff need be provided for carrying out the hearing screening, and the target group can easily be approached.

Babies who achieve a normal test result in the first or second test are further monitored in the welfare baby clinic as regards their speech and language development, in order to detect secondary hearing impairment, "late onset" hearing impairment or progressive hearing disturbances in good time. For this, use is made of a method, which systematically evaluates the development of the neuromotor system and communication and of active observation by the parents. Any suspicion or doubt on the part of the parents or team members, and any new risk involving possible hearing impairment (brain injury, meningitis, etc.) lead to a new hearing evaluation.

If a possible hearing impairment is detected at the first AABR screening ('refer' result), a second screening is carried out within 48 hours in the presence of the welfare baby clinic medical officer. The latter examines the ears with an otoscope and draws up a specific case history based on the risk list of the Joint Committee on Infant Hearing Screening.

If the second test is again positive, contact is immediately made with the family doctor or paediatrician and in mutual consultation the baby is immediately referred to a specialised referral centre or university service.

This swift referral procedure, which is subject to a strict collaboration protocol, guarantees optimal follow-up without 'losing' referred children. Thus considerable time and money are also saved for the parents in question and for the community.

The 23 university Ear Nose and Throat (ENT) departments and specialised referral centres for early monitoring, diagnosis and integral rehabilitation in Flanders are tasked with carrying out a hearing evaluation within two weeks in order to ascertain or rule out a hearing defect (case history, ENT

examination giving special consideration to known stigmata, informal and semi-objective audiometry, tympanometry, oto-acoustic emissions, threshold determination using ABR.).

Upon confirmation of a hearing defect, in a second phase additional specialised tests are carried out with a view to a comprehensive diagnosis (radiology, CT scan, (neuro) paediatric consultation with attention to the heart, central nervous system, kidneys, thyroid, with specific technical tests depending on any abnormalities found, ophthalmologic consultation, determination of the karyotype, genetic counselling). The multidisciplinary approach also begins immediately, with integral rehabilitation and home support (audiology, speech therapy, physiotherapy, teaching and psychological support and contact groups). The Algo programme manager is kept informed at every stage.

All of this is carried out in accordance with a strict protocol, which has been drawn up together with the university centres and has been endorsed by the referral centres and also by the Flemish Minister of Public Health. Only those centres that endorse this protocol are certified as referral centres.

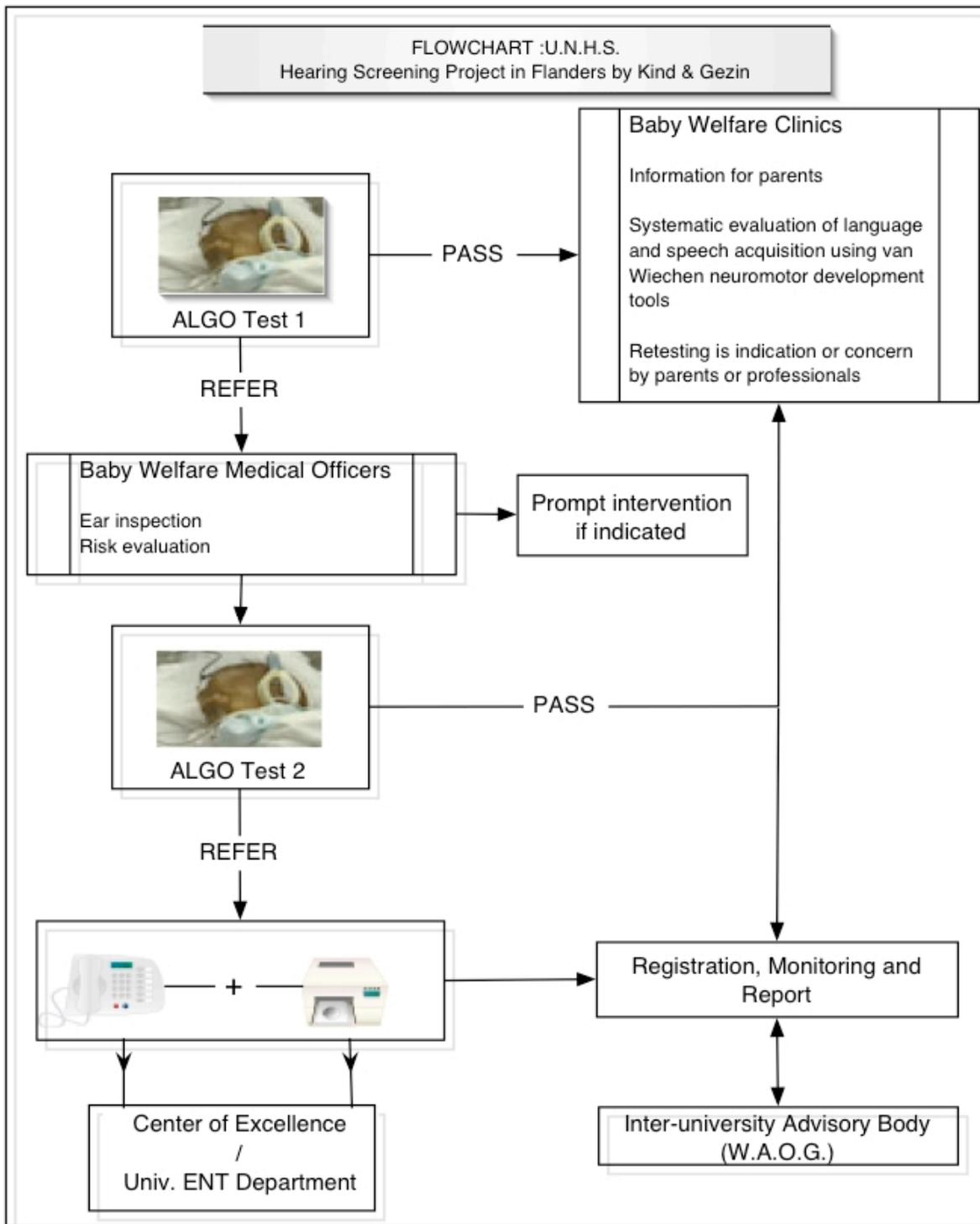
Any baby with a hearing defect should be detected before the age of three months and must be referred. In this way medical diagnostic and audiological tests can be completed before the age of four to six months in order to make optimum use of the therapeutic options.

The protocol guarantees for each child a minimum of medical and diagnostic tests and swift intervention. It is also partly due to this that to date no single child has been lost from the diagnostic and therapeutic circuit, or from rehabilitation.

The referral centres also undertake to keep both Kind & Gezin and the GP informed of the test and rehabilitation data via a standardised report. In this way a clear overview of congenital hearing impairments in Flanders is at the disposal of Kind & Gezin. The processing and interpretation of these data permits accurate evaluation of the programme and supportive control of the protocol. An inter-university Scientific Advisory Body supervises the AABR programme and makes proposals for changes.

The Flemish Ministry of Public Health and the Medical Board of Physicians approved this protocol and this preferential collaboration.

The referral centres, confronted with a very young population, also faced a new challenge: in a short time they had to develop expertise for which there was virtually no precedent. By means of mutual consultation they have streamlined the process of medical and audiological assessment, early home intervention and rehabilitation. Early screening will only be effective if follow-up will be guaranteed.



# PART 1

## ACTIVITIES AND DEVELOPMENTS IN 2000

### 1. Training and support.

Districts teams have been given the opportunity to train new staffmembers, whether to have the in field training offered by the ALGO<sup>®</sup> programme manager. The provinces of East-Flanders and Limburg had their staff members trained by the ALGO<sup>®</sup> programme manager. On all other locations the ALGO<sup>®</sup> experts trained their staff themselves, supported by the ALGO<sup>®</sup> programme manager.

The ALGO<sup>®</sup> programme manager provided direct assistance with the carrying out of 18 ALGO<sup>®</sup> tests. Often these tests had been performed earlier but resulted in a repeated abortions of testing activities or direct assistance has been offered as a result of special demands from staff or parents.

All ALGO<sup>®</sup> experts from the various provinces took part in a half-day of provincial ALGO<sup>®</sup> consultation.

### 2. The referral centres.

Attachment 1 contains the list of all 23 certified centres of Reference. This list didn't undergo substantial modifications.

The recommendation on whether or not to accept an application from a potential referral centre or to remove a centre from the list is within the remit of the inter-university Scientific Advisory Body for the Support of Hearing Screening. Advice has been given not to adopt additional Centres of Reference.

### 3. Meetings and publications.

January 28th: Kind & Gezin organised an ALGO<sup>®</sup> information session for Youth health students.

February 2nd: Kind & Gezin received a delegation from Natus Medical Inc. from San Carlos, California.

February 7th: Kind & Gezin organised an information session Women's International Contact Group at Brasschaat.

February 29th: Kind & Gezin held a guest lecture at the department of Audiology at the Lessius University from Antwerp.

March 10th: Kind & Gezin has been invited for an information session regarding Early Hearing Screening at the Euro Parliament in Brussels.

March 31st: Kind & Gezin attended the 13<sup>th</sup> Annual Workshop on Hearing Screening in Children at the Queens Medical Centre in Nottingham on invitation of prof. Adrian C Davis.

April 6th: Kind & Gezin attended the National Symposium organised by the Dutch Association of ENT Surgery on invitation of Olde Kalter in Amsterdam, the Netherlands.

May 24th: Kind & Gezin attended a meeting regarding the warranty contract at TriVirix, Belfast, Northern-Ireland.

July 5th: Kind & Gezin held a lecture for medical students from the paediatric department of the University of Louvain.

Kind & Gezin published a Dutch article "Universal Early Hearing Screening in Flanders using AABR" in the October issue of the Journal of Youth Health Care.

October 11th, Kind & Gezin attended the “Universal Newborn Hearing Screening, Programme Design and Implementation” Congress at the San Raffaele Biomedical Science Park in Milan on invitation of Professor Emerita Marion Downs.

From October 12th until 14th, Kind & Gezin attended the “International Conference on Newborn Hearing Screening, Diagnosis and Intervention” at San Raffaele Biomedical Science Park in Milan on invitation of prof. Fernando Grandori.

October 16th, Kind & Gezin held a keynote regarding the ALGO<sup>®</sup> programme for the WHO in Geneva.

October 17th, Kind & Gezin received a delegation from Natus Medical Inc., San Carlos, California regarding the future service contract with Natus Medical Inc.

October 31st, Kind and Gezin agreed the new contract with Natus Medical Inc (San Carlos, California, Cordial Medical Europe BV (Best, The Netherlands) and TriVirix/Natus’ Euro service (Belfast, Northern Ireland).

November 6th, Kind & Gezin visited the Dutch Organization for Parental and Childhood care in the Netherlands regarding newborn hearing screening projects.

November 17th, Kind & Gezin held a lecture for the Children Audiology Conference at the KAHOG, Gent.

November 24th, Kind & Gezin attended the FUP Congress “Follow-up for Preterm Babies” at the Palace of Conferences in Brussels.

December 10th, the annual meeting with all Centres of Reference took place at the Kind & Gezin Educational Centre, Kraainem.

December 14th, the ALGO<sup>®</sup> Report of the year 1999 has been presented to the Belgian Press.

Kind & Gezin agreed with the publication of “Innovation, a challenge: call from the Flemish Government” by the Administration of Science and Innovation. The ALGO<sup>®</sup> programme was added to the brochure.

#### **4. Recording of ALGO<sup>®</sup> data.**

All the numerical data were recorded via Kind & Gezin’s IKAROS databank. The data from the databank were collected on the basis of the locality, in which the baby concerned lived, and were related to the data from the databank of the National Institute for Statistics.

Close collaboration with the IKAROS-expert is key to eliminate human errors regarding data entry. This way, we can prevent inaccurate or incomplete data entered in our data management system. Consistency checks are run frequently using smart queries. The provincial departments of Kind & Gezin share their part in correcting and completing the data already entered in the system.

#### **5. The “Scientific Advisory Body for Hearing Screening”.**

On 29 November 1999 the inter-university Scientific Advisory Body for Hearing Screening” ‘wetenschappelijke adviesraad ondersteuning gehoorscreening’ (WAOG) was set up. It comprises academics from the various Flemish universities, and its aim is to monitor and advise on the Flemish programme for hearing screening.

Prof. Dr Louw Feenstra (Catholic University of Leuven) has been chairman for 2000.

#### **6. Follow-up of projects.**

The one-year collaboration project with the university ENT department of the St. Augustinus Hospital from Wilrijk in which full-term babies were given a neonatal Oto-acoustic Emissions test by one of the

hospital audiologists was ended in December 1999. The object of this project was to increase the in-house screening service of this ENT department, in combination with the follow-up programme by Kind & Gezin to ensure maximum target cover, as offered by Kind & Gezin to all babies. If the parents refused to have an OAE re-test carried out in the hospital, Kind & Gezin endeavoured to carry out an ALGO® test. The outcome of this project showed the target cover group didn't increased significantly by the extra efforts of the ENT-staff of the hospital (using extra motivational efforts of parents, better registration protocols, performing extra retests...) but a maximum target cover could be achieved primarily by the efforts of Kind & Gezin. The extra administration costs and total costs proved to be significant higher in comparison with the universal screening project of Kind & Gezin, being part of the umbrella preventive medical services offered to all babies in Flanders.

The project with the University Centre of Gent regarding posttraumatic and post infectious hearing screening using ALGO®screeners didn't caused extra screening demands. Two district nurses from the district of Gent were on standby if screening services would be asked for.

## 7. Screening of NICU babies

In 2000 Kind & Gezin agreed with all Flemish NICU's to guarantee AABR screening for these high-risk babies.:

- |  |  |
|--|--|
| <input type="checkbox"/> University Centre of Edegem               | <input type="checkbox"/> University Centre Genth     |
| <input type="checkbox"/> St Augustinushospital of Wilrijk          | <input type="checkbox"/> St. Jan hospital of Genk    |
| <input type="checkbox"/> Paolahospital of Antwerpen                | <input type="checkbox"/> University Centre of Jette. |
| <input type="checkbox"/> University Centre Gasthuisberg of Louvain |  |
| <input type="checkbox"/> St. Janhospital of Brugge                 |  |

In 2000 6 out of 8 NICU's offered systematically a hearing screening to their babies prior to their discharge. In collaboration with these NICU's Kind & Gezin developed a model to ensure a 100% cover of these high risk babies, even for those who would be missed by the NICU screening program. The results of the individual screenings are exchanged on a monthly basis between the NICU's and Kind & Gezin providing both partners a perfect overview of the actual screening status of each NICU graduate.

Due to administration inconveniences and postponed electronic file management, the start of this close collaboration program had to be postponed until 2001.

The NICU St Augustinushospital rejected this collaboration program for NICU hearing screening and thus isolated itself from the Flemish consensus for integrated hearing screening.

## 8. Miscellanea

To ensure continuity of preventive services and after consideration of the past results some students were admitted to perform hearing screenings using ALGO®screeners during summer holidays. All screenings were performed under surveillance of a district nurse of Kind & Gezin.

Three students – 2 social medicine nurses and 1 student of the department “Teaching of deaf people”- ere offered advisory services, finishing a thesis on Newborn Hearing Screening.

# PART 2 TEST RESULTS FOR FLEMISH REGION 2000

## FOREWORD

In 2000 86,7% of all women giving birth have been visited by a district nurse of Kind & Gezin prior to discharge. Each maternity ward is under surveillance of one district nurse of Kind & Gezin, closely watching each dismissal from the maternity ward of the hospital she is involved with. How frequent she visits the ward depends on the amount of weekly dismissals. The collaboration with Kind & Gezin is part of the quality decree for Health Care Professional Services in Flanders. It is of any importance for each maternity ward to sign for the quality decree with Kind & Gezin.

Each screening project aiming at universal early hearing screening services should ensure a maximum of target cover. From a scientific point of view only some screening methods are approved to perform the hearing screening on newborns Auditory Brainstem Response (ABR or BERA), Automated Auditory Brainstem Response (AABR, brand ALGO<sup>®</sup>) Oto-Acoustic Emissions (OAE - T.E.O.A.E or D.P.O.A.E).

In 2000 OAE-tests has been offered to all newborns of the Saint Augustinushospital from Wilrijk (being part of a collaboration protocol with Kind & Gezin), the local hospital from Aalst and the Imelda hospital from Bonheiden.

The situation in the maternity wards in the Brussels Capital Region still keeps very uncertain. Hospitals choose not to inform parents on which test has been offered to their babies. Therefore, Kind & Gezin, not being informed accordingly, offers an ALGO<sup>®</sup> screening to all babies after discharge from a Brussels Maternity ward. Also offering screening tests to all babies isn't ensured. Central registrations missing. Follow-up and quality control aren't provided in these local projects.

Even if a valuable neonatal hearing screening shows a unilateral failure, parents will be motivated by kind & Gezin to have a retest performed in close collaboration with the maternity ward and ENT-department of the hospital of medical centre.

Eventually Kind @ Gezin will perform the retest and inform the maternity ward and ENT-department of the hospital of medical centre accordingly.

To maximise target cover a close watching program was set up for young children of asylum seeking parents and also for those who are staying illegally in the Fleming region. ALGO<sup>®</sup> screening will be offered to all babies until the age of 4 months (6 months for NICU graduates).

# REGISTRATION OF ALGO<sup>®</sup> SCREENING DATA

All the numerical data were recorded via Kind & Gezin's IKAROS database.

The data from the databank were collected on the basis of the locality, in which the baby concerned lived, and were related to the data from the databank of the National Institute for Statistics.

Neither the tests carried out externally (outside the collaborative project) nor the tests on high-risk babies who were long-term patients in the neonatal intensive care units have been processed in this report.

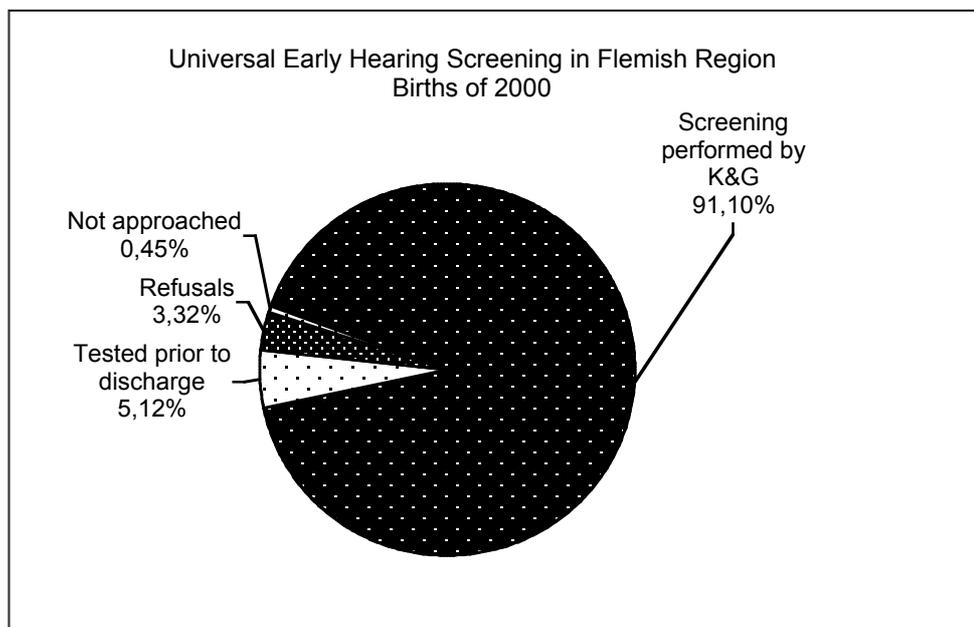
After every positive test the district nurses make contact via the ALGO<sup>®</sup> help-line. The district team thus receives extra support for every 'refer' test and for every referral, while the referral databank remains very accurate.

All have been collected in relation to the habitat of the baby involved and these data have been correlated to the database of the National Institute for epidemiological Statistics, containing the data of all inhabitants of the Kingdom Belgium. For reason Kind & Gezin and the N.I.S are using different geographical entities, some data of the provinces of Antwerp and East-Flanders may suffer from some restrictions

Advanced queries have been integrated in our data management to prevent double registration occurrence. Each district has been monthly questioned about the processing of missed babies in the past period. These objectives have always been chased with highest priority.

No external tests neither results of hearing screenings tests performed on a NICU population have been added to this report.

In 2000, 55,999 babies were screened in the Flemish Region using the ALGO<sup>®</sup> screening. The two Districts of the Brussels Capital Region are hard to compare with the provinces of the Flemish Region, due to the smaller cover of the French speaking clients and the concurrency of the O.N.E., the French speaking sister organisation, serving the French speaking part of Belgium, the no-admittance policy of the French speaking maternity wards towards Kind & Gezin and the high amount of immigrants.



**Chart 1 : Proportion of families approached for an ALGO<sup>®</sup> screening**

## 2. Test results in the Flemish Region 2000

Only babies we tested ourselves have been included in this report. N.I.C.U. graduates have been excluded to this report as well as those tests carried out at the maternity ward (except for the collaborative project).

### 2.1. Overview of all districts (not included district Brussels I & II)

#### TARGET GROUP COVER

Number of births:	61.877	
Number of perinatal deaths:	410	
Number of babies to be examined	61.467	
<b>Babies tested by K&amp;G:</b>	<b>55.999</b>	<b>91,10%</b>
Refusals for test	2.043	3,32%
Already tested on maternity ward	3.146	5,12%
<b>Number of approached babies</b> (= Test offered)	<b>61.188</b>	<b>99,55%</b>
<b>Number of not covered babies</b>	<b>279</b>	<b>0,45%</b>

#### TEST OUTCOMES

• Number of first tests	<b>55.999</b>	
Pass with the first test	55.683	
Refer with the first test	316	= <b>0,56%</b> (refer ratio after first test)
• Number of babies re-tested (foll. test 1):	<b>316</b>	
Pass with the second	203	64,24% of test 2
Referred babies after test 2	113	35,76% of test 2
• Total number of babies referred	<b>113</b>	= 2,01 per 1000 / 1 <sup>st</sup> tests
• Total number of babies to be re-tested:		
“Refers” with the first test	316	0,56%
Incomplete tests	1.893	3,38%
Babies to be retested	2.209	3,94%
• Total tests carried out	59.475	
(test 1 + “refers” first test + incomplete 1 of more+ test on special demand+ tests of non target group)		

<b>TARGET GROUP COVER</b>	<b>1998</b> (in operational districts)	<b>1999</b> (in all Flemish districts)	<b>2000</b> (in all Flemish districts)
Number of babies tested by K&G	38.048	55.388	55.999
% Of population tested by K&G	87,66%	90,04%	91,10%
Refusals for test	2,73%	3,13%	3,32%
Totaal bereikte baby's	93,87%	98,00%	99,55%
<b>TEST OUTCOMES</b>	<b>1998</b>	<b>1999</b>	<b>2000</b>
Refer rate 1 <sup>st</sup> test (% of 1 <sup>st</sup> test)	0,37%	0,76%	0,56% (n=316)
Refer rate 2 <sup>nd</sup> test (% of 2 <sup>nd</sup> test)	44,29%	29,83%	35,76%
Total of babies referred in ‰	1,7‰ (n=64)	2,3‰ (n=125)	2,0‰ (n=113)
Incomplete tests	2,1%	3,8%	3,4%

**Chart 2 : Comparison of target group cover and test outcomes in 1998, 1999 and 2000 with ALGO<sup>®</sup>test.**

2000 brought us a 'refer' ratio following the first test as low as 0,56%. The "Year 2000 Position Statement" of the Joint Committee on Infant Hearing (J.C.I.H.) emphasizes referral ratio's shouldn't be as high as 4% in the years following implementation. The European Consensus Statement (Milan, 2000) also confirms this statement. The Universal Early Hearing Screening project of Kind & Gezin meets these demands and shows a referral ratio after 2 sequential screenings of 0,20%. As far as we know, this low referral ratio is quite unique.

The median age for performed screening tests was 27 days.

Tests lasting 20 minutes or more have been aborted in order not to disturb the normal workload of the district nurses. A new appointment is always given after each incomplete test.

3,38% of babies was subject of incomplete tests. This raises the total amount of babies who had to be retested to 2209 or 3,94% of the babies who underwent a first test.

The referral ratio after 2 tests averages 35,76% in 2000. Over one third of babies with a 'refer' result with the first test got also a 'refer' result with the second test

## 2.2. Target group cover

In 2000, 61,877 births were recorded in the Flemish Region (data from October 2001). The number of newborns who died prior to early hearing screening was 410; so 61.467 babies were eligible for screening.

A screening offer has been made to 99.55% of the eligible babies, which is an increase of 1.55% since 1999. The districts still made maximisation of target group cover their primary objective for 2000.

The motivation of our district nurses, the great acceptance of the ALGO<sup>®</sup> test by parents, the close search for missed babies and the accurate registration and follow-up are key factors to achieve this result. Refusals for test have been registered rarely. Sometimes, babies passed a screening test prior to discharge without proper knowledge of the parents. Taking in consideration not all offered screening tests meet the demands of the European Consensus Statement, Kind & Gezin made the choice to retest each baby when the quality of the screening test in the maternity ward couldn't be ascertained;

Parents refusing a retest for their baby who passed prior to a not specified test were more likely to refuse for an ALGO<sup>®</sup> retest. This situation is very common in maternity wards of the Brussels Capital Region.

In 2000 Kind & Gezin itself screened 55,999 babies or 91.10% of the target group, which represents an increase of 1.06% in comparison with 1999.

The two districts of the Brussels Capital Region screened together 1.193 babies.

Median age averages 29 days as proposed by the instructions of kind & Gezin. Our pilot from 1999 showed tests lasting less when performed at age from 4 until 6 weeks, meeting the planning for the house calls for parents with a first (2nd house call @ 4 weeks) or following child (2nd house call @ 6 weeks).

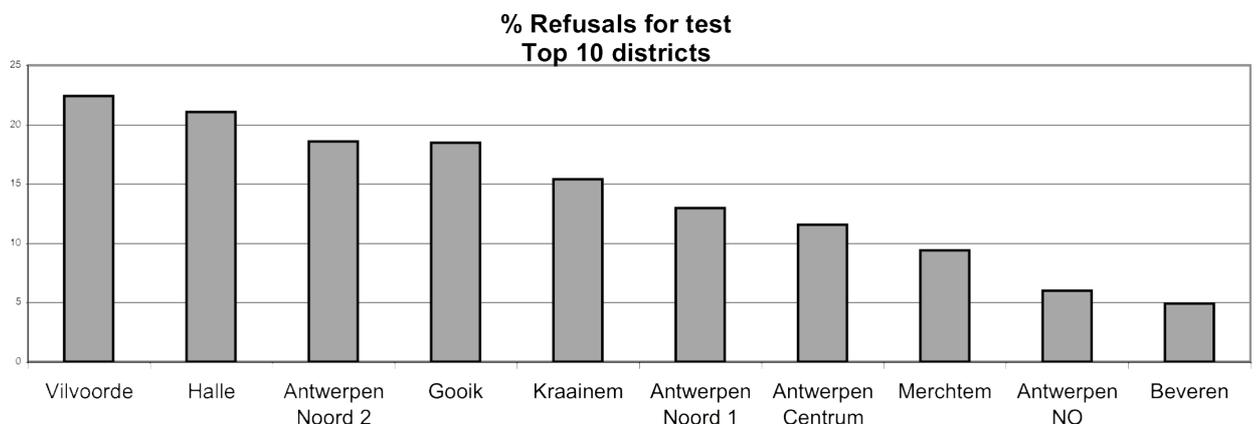
In total 59,475 ALGO<sup>®</sup> tests were undertaken by Kind & Gezin or its partners in the Flemish Region.

## 2.3. Refusal for ALGO<sup>®</sup> test

In 2000 also, some parents refused to have an ALGO<sup>®</sup> test carried out. The main reasons given are not different from those shown in earlier reports: "not interested", "a reflex test was carried out during the stay in the maternity ward", "my paediatrician will perform a hearing screening test" and "special issues" such as holiday, emigration are common causes for refusal for test.

2,043 refusals of ALGO<sup>®</sup> screening have been recorded or 3.32%.

The database system itself is also cause of high refusal ratios. Each missed baby is automatically reported to the district involved with its preventive medical care program. If parents are apparently unreachable by house call or phone and do not respond on several written invitations and phone calls, district nurses are not allowed to have the planned preventive services postponed over a long period. Due to the not responsiveness of parents and lack of time, a refusal may be entered. A random sample survey showed parents are given the refusal status if they don't respond after four or even more invitations by phone or letter. This approach allows the district to delete clients from the monthly-generated watch lists if they don't respond to offered screening services



**Chart 3: Refusals for test showing decreasing percentages for top 10 districts involved (% of the approached cohort)**

We have to take in account the high amount of refusals for some populations. Results from districts show important differences in refusal status (Chart 3).

Province	ALGO® by K&G			Refusals			Tested prior to discharge		
	1998	1999	2000	1998	1999	2000	1998	1999	2000
Antwerp	87,04	84,03	88,44	3,82	3,18	3,16	4,92	10,75	10,94
Limburg	92,25	96,52	97,46	1,15	1,59	1,40	0,69	0,96	0,95
East-Flanders	91,97	94,02	96,90	2,45	2,08	1,87	1,94	2,81	1,23
West-flanders	91,76	95,67	98,44	0,76	1,16	1,50	0,11	0,05	0,06
Flemish-Brabant	74,73	83,47	81,47	3,49	7,80	8,47	7,63	5,64	9,11
Brussels Capital Region	47,23	59,66	71,72	2,49	31,63	23,28	0,78	1,17	1,59

**Chart 4: Overview of target covers for the provinces from 1998 until 2000: tested by K&G, refusals and tested prior to discharge.**

#### 2.4. Screening tests performed by maternity ward staff.

Click-evoked oto-acoustic emissions (C.E.O.A.E.), distortion-product-evoked oto-acoustic emissions (D.P.O.A.E.) and standard or automated brainstem response audiometry (A.B.R. or A.A.B.R.) are among the valid hearing tests which may or may not occasionally be carried out on newborns in maternity wards.

In 2000 a total of 3,146 valid hearing tests for neonates were recorded as carried out externally. This represents an increase of 5.9% over 1999.

The Saint Imelda hospital at Bonheiden and the local hospital at Aalst offered hearing screenings using O.A.E. of ALGO® technology to their new-borns. The test results haven't been shared with Kind & Gezin so we are uncertain if hearing impaired children have been diagnosed in these centres. The Saint Augustinus hospital from Wilrijk stopped out their local O.A.E. project for well babies since October 2000. An ALGO® test after discharge has been offered to all babies who were missed by these local projects.

The districts from the Antwerp Region are more often confronted with hearing screening tests prior to discharge. Also the districts of Haacht, Halle and Vilvoorde are reporting they are more frequently now confronted with hearing screening tests prior to discharge. (Chart 4).

Chart 4 shows the amount of neonatal hearing screenings in the provinces of Limburg, East-Flanders and West-Flanders (0.95%, 1.23% and 0.06%.

## **2.5. Babies not approached by Kind & Gezin (no screening offered).**

Kind & Gezin approached not all newborns. Exactly 410 babies died before they could be tested. For 279 babies or 0.45% of the target group, it did not prove possible for the districts to offer a hearing test.

One important element of this is the N.I.C.U. babies who are long-term patients in neonatal intensive care.

By carrying out systematic databank checks on unscreened babies and monthly reports on the missed babies to all districts, it was possible to reduce the number of not approached babies in 2000 by 1.55%.

### 3. Screening, deprivation and ethnicity

In the Flemish Region 3.643 babies were born in 2000 into underprivileged families (these are families with young children which are monitored by Kind & Gezin and which, according to standardised and scientifically based criteria, are in a multi-aspect poverty situation – source: Kansarmoedeatlas 1999, Kind & Gezin. Kind & Gezin screened 2,617 of these babies or 85.19% using the ALGO® test.

UNDERPRIVILEGED FAMILIES	AMOUNT	% Underpriv.	For comparison % of total population
Babies born in 2000 into underprivileged families	3.643	100%	100% (n=61.476)
ALGO®-screening carried out by K&G	3.016	82,79%	91,10%
Refusal for ALGO® test	267	7,33%	3,32%
Hearing screening performed prior to discharge from maternity ward	60	1,65%	5,12%
ALGO® test offered by K&G	3.343	91,77%	99,55%
Babies not approached	300	8,23%	0,45%

Chart 5: Target group cover for hearing screening in babies born in 1999 into underprivileged families.

In this target group 267 refusals for ALGO® test were recorded (7.33%). 60 babies or 1.65% out of this target group already passed a neonatal hearing screening prior to their discharge. Target cover for the underprivileged families averages 91.77%. It is clear 300 babies didn't received a screening offer. It was expected only 16 out of this group would be missed by the program, taking in account the average non-cover percentage for the Flemish population.

There are also noticeable differences according to ethnicity as regards refusal of ALGO® hearing screening. The nationality of the mother at birth was taken as the main criterion..

Ethnicity	Births	% refusing ALGO®
Moroccan ethnicity	1.828	3,01%
Turkish ethnicity	1.715	0,76%
Other non-Belgian ethnicity	5.248	4,63%
Belgian ethnicity	50.035	2,13%

Chart 6: Number of refusals of ALGO® screening by ethnicity in 2000

## **4. Referral results for the Flemish Region 2000**

### **4.1 Introduction**

The number of babies born in 2000 who were referred after a repeated positive ALGO<sup>®</sup> result was 113. A welfare baby clinic medical officer referred each of these babies to one of the 23 Flemish referral centres for Kind & Gezin in consultation with the GP, for diagnostic tests and/or integral support and rehabilitation.

The appointment at the referral centre was in all cases made by the Kind & Gezin welfare baby clinic medical officer, giving the parents the date, time and the name of the person whom the parents would meet. If parents did not come to the first or a subsequent appointment, the district nurse contacted the parents and arranged a new appointment. If further follow-up was broken off, a suitable solution was sought in consultation with external services and the ALGO<sup>®</sup> Programme Manager.

Families with a baby with an early diagnosis of hearing impairment received special attention and support from Kind & Gezin. Over and above the basic care services these families were eligible for specific care services consisting of extra home calls and consultations, in which the welfare baby clinic team tailored the services to the individual needs.

The referral centres undertook to report the results of diagnoses, support and integral rehabilitation to the attending physician and to Kind & Gezin. The processed results were submitted to the Scientific Advisory Body for Hearing Screening, and following approval were made available to the referral centres.

### **4.2 Choice of referral**

The choice of referral centre was largely determined by the preference of the parents and the attending physician. The Baby Welfare Medical Team doesn't show any preference when parents are informed how to get in touch with the specialised centre.

Some centres are more specialised, or exclusively specialised, as diagnostic centres and therefore receive many primary referrals. Centres whose competence is more in the field of rehabilitation or support receive more secondary referrals. Chart 8 shows the cumulated amount of primary and secondary referrals for 1998, 1999 and 2000..

The by the Ministry of Health certified centres for early home guidance are still experiencing parents opting for famous medical centres although they perform assessment services in a joint venture with these centres. These centres are highly qualified to offer support and home guidance made to measure and offer these services from the early start of the audiological assessment process. These centers are marked with an asterisk in chart 7.

Center of Excellence	Location	Primary referrals 1998-2000	Secondary referrals 1998-2000	Total amount of primary and secondary referrals
Royal Institute Spermalie / Early Home Guidance Centre (*)	Bruges	30	7	37
University Rehabilitation Centre for Hearing and Language disorders	Louvain	30	2	32
Rehabilitation Centre St Lievenspoort / Early Home Guidance Centre (*)	Genth	19	12	31
Univ. Rehab. Centre for Communication Disorders UZA	Edegem	25	5	30
University ENT-department van UZGenth	Genth	26	1	27
University ENT-department van St. Augustinus Hospital.	Wilrijk	24	0	24
Royal Institute for Deaf and Hearing Disabled Children (KIDS)/ Early Home Guidance Centre (*)	Hasselt	15	9	24
University ENT-department of Middelheim Hospital	Antwerp	22	0	22
University ENT-department of Children's Hospital VUB	Jette	20	1	22
Hearing Centre Overleie / Rehab. Centre Auricula	Courtrai	18	1	19
North Star Centre for hearing, language and visual disabilities	St Ag. Berchem	9	7	16
East-Limburg hospital Campus St. Jan (ZOL)	Genk	15	0	15
Virga Jesse Hospital	Hasselt	12	0	12
Early Home Guidance Centre Jonghelinckshof (*)	Antwerp	7	2	9
ENT-department of. Maria Middelaes Hospital	Genth	9	0	9
Centre for Hearing and Language disorders	Oostend	7	1	8
Royal Institute for Sensory Disabilities (*)	Woluwe	5	2	7
Centrer Ter Kouter / Language Rehabilitation Centre	Deinze	3	4	7
St Lucas St Jozef Hospital	Bruges 4	3	1	4
County Hospital Aalst	Aalst	2	0	2
St Jan Hospital	Bruges	1	0	1
Rehabilitation Centre De Klinker /Healthcare East Coast	Heist-a-zee	0	0	0
<b>Total</b>		<b>302</b>	<b>55</b>	<b>357</b>

**Chart 7. Overview of referrals to Centres of Excellence 1998 - 2000 per referentiecentrum**

### 4.3 Referral results by incidence and degree of hearing impairment

As already mentioned above, in 2000, 113 babies were referred to a referral centre following a repeat positive ALGO® test. All the babies referred were monitored by Kind & Gezin to ensure appropriate follow-up and reporting, and so that no results were lost.

Hearing impairment was confirmed in 102 or 90.27% of the 113 babies referred. In 11 babies or 9.73%, normal hearing was reported after referral.

Assesment follwing referral	Number	%
Ascertained PCHI	<b>102</b>	90,27%
Normal hearing	11	9,73%
<b>Total</b>	<b>113</b>	<b>100%</b>

**Chart 8: Overview of actual positive and false positive screening results according to reports of the referral results in 2000**

Normal hearing has been established for only 11 babies following two stages AABR-screening representing approximately 2 in 10,000 of the babies examined. The group of 107 babies with ascertained hearing impairment was divided according to the incidence of unilateral and bilateral

hearing impairment. This difference is important for the referral centres as regards deciding whether or not to apply further diagnostic means, and whether or not to commence integral support/rehabilitation.

For 56 babies out of the cohort of 102 babies diagnosed with Permanent Childhood Hearing Impairment (P.C.H.I.) a bilateral hearing impairment was ascertained. This gives the figure of 54.90% of all ascertained PCHI cases.

Other authors also mention a high participation of unilateral hearing losses in the group with ascertained hearing impairment, with a 50/50 % rough estimated participation. (Yoshinaga-Itano C., Colorado project 1998, Neumann K., Hessenproject 1998).

Cases of diagnosis of hearing impairment	Unilateral hearing impairment	Bilateral hearing impairment	Total	%
Hearing impairment classified audiological	43	53	96	94,1%
Hearing impairment (as yet) not classified audiological	3	3	6	5,9%
<b>Overall total</b>	<b>46</b>	<b>56</b>	<b>102</b>	<b>100%</b>

**Chart 9 : Overview of the 102 cases of hearing impairment in 2000 by whether or not classified.**

The participation of unilateral ascertained hearing losses didn't changed significantly over time. The same conclusion can be drawn regarding the total number of ascertained babies with PCHI > 40dB for the non-NICU population. (chart 10).

PCHI	1998 (implemented districts)	1999 (Flemish Region)	2000 (Flemish Region)
Ascertained PCHI following referral	87,9%	85,6%	90,27%
Participation	52,9% unilateral 47,1% bilateral	48,6% unilateral 51,4% bilateral	45,1% unilateral 54,9% bilateral
# per 1000 bilateral PCHI > 40dB	(0,6‰)	0,8‰	0,8‰

**Chart 10: Comparison on PCHI in 1998, 1999 and 2000 following ALGO®-screening.**

In 2000 94,1% (n=96) of the 102 babies with ascertained hearing impairment have been audiological classified. Classification of hearing impairment in young children isn't an easy job especially with babies who suffer from multiple disorders (Chart 12).

Classified cases of hearing impairment based on BERA threshold	Unilateral PCHI	%	Bilateral PCHI	%	Total
21-40 dB	11	25,58	5	9,43	16
41-70 dB	23	53,49	25	47,17	48
71-90 dB	5	11,63	7	13,21	12
>91 dB	4	9,3	16	30,19	20
<b>Total</b>	<b>43</b>	<b>100</b>	<b>53</b>	<b>100</b>	<b>96</b>

**Chart 11 : Overview of the 96 cases of classified PCHI according to the BERA threshold in 2000**

#### 4.4 Incidence of PCHI

In 2000 permanent childhood hearing impairment of at least 40 dB F.I. for the best ear was demonstrated with certainty in 48 babies. In 3 babies with bilateral hearing impairment the degree could not be classified. This brings the incidence of perceptible hearing impairment to 0.86 per thousand. The data from 1999 showed an incidence of 0.83 per thousand. The number to be expected in a total population is 1 in 1000, which for the population tested by K&G amounts to 55.

A risk population, however, shows a prevalence of 1 to 3 in 100. The risk population consists in particular of premature babies in one of the 8 Neonatal Intensive Care Units (NICU's). In the Flemish Region, the number of NICU babies' averages 2500/year, some of them requiring long-term hospital care. Among these then, a further 20 or so cases of hearing impairment may be expected. As yet this group has received only limited hearing impairment testing and almost never from K&G. They are therefore excluded from this report. In future, arrangements will be made with all NICU departments in Flanders for hearing screening of this population and recording thereof.

We expect to show accurate data regarding screenings of high-risk population from 2002 on. A weighted extrapolation of incidence of PCHI in NICU graduates to all newborns shows an incidence of 1.44 pro mille in the overall population. We expected to be reported on some babies with PCHI who have been registered as "refusals" as well as babies who were missed by local hospital based screening programs. Recently, a three year old toddler was ascertained with bilateral PCHI > 80 dB after being missed by the local hospital screening project which focuses their own NICU babies, screenings being planned prior to discharge. This disastrous example proves the importance of a guard network to follow-up NICU-graduates who would be missed by local screening projects. If Kind & Gezin would have been informed by the NICU on the non-screened status of this graduate, this baby would have been chased and traced by our district nurses to motivate parents to have their baby screened.

Screening result vs. audiological assessed unilateral/bilateral hearing impairment	Referral following Unilateral refer	Referral following Bilateral refer	Total
Ascertained unilateral PCHI	43	0	43
Ascertained bilateral PCHI	8	45	53
All Cases	51	45	96

**Chart 12 : Verband lokalisatie Refer bij screening en lokalisatie van het bevestigde gehoorverlies in 2000.**

51 babies or 53.12% of the total referred population have been referred due to a repeated unilateral ALGO® result. 45 babies or 46.88% have been referred due to a repeated bilateral ALGO® result. Audiological assessment showed a unilateral hearing impairment in 43 babies of 44.79% from this cohort and ascertained a bilateral hearing impairment in 53 babies or 55.21%, which is remarkable. 8 babies or 8,33% who have initially been referred due to a repeated unilateral refer for hearing screening are ascertained with a bilateral PCHI. Three out of these 8 have been infected during pregnant by CMV. Clinical results from the 5 other babies are missing at present.

Recent studies show indications for progressive hearing impairment caused by CMV-infections sometimes without detectable hearing disorders in the neonatal period. This emphasizes the importance to follow-up babies who passed a neonatal hearing screening. It also motivates for close follow-up of babies with ascertained unilateral hearing disorders. In 2000 Kind & Gezin implemented the Van Wiechen neuromotor development instrument in all Baby Welfare Clinics, which is most appropriate to evaluate language and speech acquisition skills.

Based upon these findings it would be a misconception to question the validity of a hearing screening method or instrument.

#### 4.5 The rehabilitation and support phase

The referral centres made 34 rehabilitation reports concerning babies born in 1999 with diagnosed hearing impairment after an Algo referral. According to the present protocol, an initial rehabilitation report is not expected until 6 months after confirmation of the diagnosis and onward referral.

A retest after first refer result is planned within 48 hours. So parents aren't kept uncertain over a long period. The prompt referral after second refer result keeps parents from shopping for services. It is not evident to make parents comply to the protocol if they have already contacted some not certified centres. To accommodate parents confronted with a referral some centres of excellence offer early home guidance services from the earliest start, even before hearing disorders could have been ascertained.

At least every family with a hearing-impaired child should have early home guidance been offered as soon as hearing impairment has been ascertained.

A close look at the data of 23 referred babies with PCHI shows only 56,3 days (SD 63.9) elapsed on average from referral by Kind & Gezin to start of the rehabilitation process within a range of 1 to 268 days.

We investigate also time elapse between first consultation in a centre of excellence and start of the rehabilitation for babies with ascertained bilateral hearing impairment > 40 dB F.I. In a cohort of 21 babies with extensively reported data elapsed 66,6 days on average (SD 67.9) from first consult to start of the rehabilitation process with a range from 1 day to 268 days. This last figure may seem very important but was reported as due to an eight month trip by a family who moved over temporarily

Even time elapse between screening time and the moment hearing aids were introduced has been investigated. In 12 babies hearing aids have been introduced on average 144 days (SD 151) after referral by Kind & Gezin within a range from 18 to 433 days. Last case concerned a baby with a moderate hearing impairment who seemed to have some benefit using a hearing aid. As the hearing impairment was quite moderate, it wasn't obvious to offer a hearing aid to this baby.

From the first consult in the centre of excellence, audiologic assessment is a high priority to get an impression of the hearing impairment. Early home guidance is also offered immediately to support the family involved, offering pedagogic and communicative advise, help with the acceptance process and dealing with the disability as well as stimulating a positive growth enabling environment. Hearing aids are fitted in close communication with parents. This will have effect of the introduction time of hearing aids. Follow-up is of utmost importance over a long period to fine-tune the hearing aids to babies' disability and comfort as well as to get a close picture of the hearing impairment.

The audiological consults alternates from pure tone audiological assessment using headphone, insert earphones, bone conduction and tonal audiological assessment using hearing aids.

Supra-liminary tests using hearing aids are also included in the assessment protocol. Early home guidance, rehabilitation and psychological and pedagogical support by external caretakers are fine tuned to each other. Parental participation is key to fully exploit babies' rehabilitation potential

Some of the early-detected babies already got a cochlear implant. For 5 babies, we could trace time elapse from referral to implantation showing a figure of 293 days average time (SD 108) within a time range from 234 to 484 days following referral.

Three babies returned their hearing aids when it became clear the hearing disorder didn't made a hearing aid necessarily any longer. The ascertained hearing loss seems to have be developing within normal range for these three babies. It is still uncertain if early stimulation leads to this remarkable result whether audiological assessment played a part although no elements could be found indicating inaccurateness in assessment procedures. Two other babies however returned also their hearing aids when it became clear their hearing capabilities evolved very positively due to the intensive rehabilitation and therapy or rehabilitation has been completely stopped.

The results of the babies who are in the rehabilitation process speak for themselves. Centres of Excellence are reporting early detected babies are performing extremely well. The initial reserve has changed dramatically now professionals report how enthusiastic they get confronted with the progress the early-detected babies make. Some report some babies are a little ahead in language and speech acquisition compared to their non-hearing impaired brothers and sisters

Also babies with cochlear implant are performing extremely well. Parents get confidence in the implantation technique and some of them start demanding for a bilateral cochlear implant. As cochlear implants don't last forever and the technique is quite invasive it is appropriate to warn for over consumption. Future developments may possibly suffer from hurriedly actions from the past that obstruct new techniques from implementation.

Early home guidance services mention in their annual reports no single hearing disabled children entered school for the deaf since the start of UEHS. The motivation and efforts of parents and the direct surroundings of the child involved is key to the benefit of early detection and rehabilitation. This engagement is necessary to exploit children's capacities and talents in live.

# SUMMARY AND CONCLUSIONS

The data show that the Flemish hearing-screening programme is efficient and has achieved virtually maximum target group cover in the non-high-risk population. Kind & Gezin approaches almost all young families on the basis of its government assignment. By using the birth data from the National Institute for Statistics, and the screening data from the Kind & Gezin IKAROS databank, it was possible to obtain very accurate data. The logistical aspects of the Algo programme are conclusive and are controlled via a databank. The collaboration with all NICU's is key to guarantee future follow-up of all high-risk babies.

Target group cover rose again in 2000 and reaches 99.55% of all babies born in the Flemish region. In the interests of maximum cover, particular attention must be devoted to the underprivileged population, in which cover is currently lower than for the average population. There are also more refusals from parents of non-Belgian ethnicity other than Moroccan and Turkish.

The ALGO<sup>□</sup> programme manager is essential to realise a high cover for this screening project. The monthly lists of babies who have not yet been screened are also an important instrument for increasing the level of cover. All districts are made responsible to offer all babies an early hearing screening.

113 babies were referred to one of the 23 referral centres in Flanders after two positive ALGO<sup>□</sup> tests. In 102 babies, or 90.3%, hearing impairment was confirmed. In 56 this impairment was bilateral, in 46 unilateral. The number of babies ascertained with bilateral hearing impairment of at least 40 dB F.I. for the best ear was 48, which represents an incidence of 0.86 ‰ of the population tested. The majority of high-risk premature babies did not have their hearing tested, and are therefore not included in this report. The incidence of congenital hearing impairment in this target group is 1 to 2%. Collaboration with the Neonatal Intensive Care Units will therefore be extended in the near future in order to monitor this high-risk group closely. Taking in consideration the incidence of PCHI in the NICU population we estimate the incidence of PCHI in the total Flemish population as 1.44‰.

For eight babies with a unilateral refer a bilateral hearing impairment has been ascertained. Three out of these have been diagnosed with CMV. Further investigations are necessary to establish the incidence of CMV infections in babies with positive hearing screening.

The number of 'refers' results after a first ALGO<sup>®</sup> test was very low in the Flemish programme (0.76%), considerably lower than the 2 to 3% found in the scientific literature on this subject. The strict standardisation, the implementation by district nurses, and the observance of strict protocols are undoubtedly some of the reasons for this. This keeps down the cost price of the test and contributes to good acceptance of the test procedure by parents and the medical profession. Nor do the referral centres suffer any extra burden

Although the ALGO<sup>®</sup> test is a highly sensitive screening a false negative result has to be taken in consideration. In 2000 no false negative case has been reported by one of the centres of excellence or at the central registration point for not-detected PCHI.

In the annual report 1999 we made mention of a possible false negative result following ALGO<sup>®</sup> screening. This baby has been ascertained with a mixed hearing loss; the sensory neural component was inferior to the intensity of the used screening method (AABR). The occasional conductive loss made the baby fails for the audiological assessment. Being treated for conductive hearing loss, the babies hearing was within the normal range.

The specificity of the Algo test is also very high but cannot prevent babies being referred wrongly after a false positive test. In 2000 only 11 babies referred after a second test proved to have normal hearing. For a population of 55,999 tested babies this means that only approximately 2 in 10,000 of the babies examined were referred needlessly.

Kind & Gezin also has a tradition of collaboration and consultation with universities and organisations. The early notification and involvement of all university ENT departments and the most important rehabilitation centres and the joint drafting of the protocols have had a positive influence on acceptance by GP's and specialists. This collaboration has now been made permanent in the inter-university Scientific Advisory Body for Hearing Screening This Board of Scientist met four times in 2000. The involvement of the attending physician in every referral not only guarantees the follow-up of the child and the family, but also supports the programme. Owing to the obligation to report on the part of the referral centres and the permanent records, there is feedback to the field of action and the attending physicians. In this way it was possible to provide optimal care services for the 113 babies who were referred after a repeat positive Algo test, and particular attention was devoted to ensuring that nobody slipped through the net.

Three Task Forces saw the light in 2000 that fine-tuned the collaboration on medical and audiological assessment, integrated rehabilitation and reporting to all partners involved.

In 2000 Prof. Dr Fernando Grandori, Chairman of the biennial "International Conference for Newborn Hearing Screening" in Como, called the Flemish Programme "the ideal model for Universal Early Hearing Screening".

This program evolved over time and some colleagues refer now it as "the best run programme in the world" but this could never have been achieved without the excellent and constant dedication of all partners and co-workers.

# ATTACHMENT 1

## YEAR 2000 POSITION STATEMENT: PRINCIPLES AND GUIDELINES FOR EARLY HEARING DETECTION AND INTERVENTION PROGRAMS.

The Joint Committee on Infant Hearing (JCIH) endorses early detection of, and intervention for infants with hearing loss (early hearing detection and intervention, EHDI) through integrated, interdisciplinary state and national systems of universal newborn hearing screening, evaluation, and family-centered intervention. The goal of EHDI is to maximize linguistic and communicative competence and literacy development for children who are hard of hearing or deaf. Without appropriate opportunities to learn language, children who are hard of hearing or deaf will fall behind their hearing peers in language, cognition, and social-emotional development. Such delays may result in lower educational and employment levels in adulthood (Gallaudet University Center for Assessment and Demographic Study, 1998). Thus, all infants' hearing should be screened using objective, physiologic measures in order to identify those with congenital or neonatal onset hearing loss. Audiologic evaluation and medical evaluations should be in progress before 3 months of age. Infants with confirmed hearing loss should receive intervention before 6 months of age from health care and education professionals with expertise in hearing loss and deafness in infants and young children. Regardless of prior hearing screening outcomes, all infants who demonstrate risk indicators for delayed onset or progressive hearing loss should receive ongoing audiologic and medical monitoring for 3 years and at appropriate intervals thereafter to ensure prompt identification and intervention (ASHA, 1997). EHDI systems should guarantee seamless transitions for infants and their families through this process.

Appropriate early intervention programs are family-centered, interdisciplinary, culturally competent, and build on informed choice for families (Baker-Hawkins and Easterbrooks, 1994). To achieve informed decision making, families should have access to professional, educational, and consumer organizations; and they should have opportunities to interact with adults and children who are hard of hearing and deaf (Ogden, 1996; Thompson, 1994). Families should have access to general information on child development and specific information on hearing loss and language development. To achieve accountability, individual community and state, health and educational programs should assume the responsibility for coordinated, ongoing measurement and improvement of EHDI process outcomes.

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