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Sehr geehrter Herr Doktor Paditz,

first of all you have to know that I am quite impressed by the outstanding quality. You, and the colleagues behind you, certainly do confirm the reputation of German Gründlichkeit und Sorgfältigkeit. **It's wonderful and very interesting there has been established a consensus in Germany. Even so that you have been able to recruit so many professionals who, with the support of parents, are dedicated to carry it out.** I read all your plans carefully, which led to the conclusion that hardly anything could be added to it. For Germany the challenge is tremendous!

It seems to me you overestimate the credits of our Dutch foundation. The Netherlands is a small country. The Bundesrepublik Deutschland in fact exists of 16 of those countries. It would be too simple to expand the Dutch performance and experiences to the scale you need. You have to cope with a variety of governments, laws and cultures, customs and traditions. The German foundation will be confronted with a much wider span of control as I am used to; your needs of money will by far exceed our demands and the German juridical conditions will undoubtedly be different. An important difference seems to be the greater distance between medical doctors and patients in your country.

Allow me to next explanation of the situation in the Netherlands:

First the latest news: The most recent figure of SIDS incidence by the Dutch Central Bureau of Statistics again show some progress: **in the year 2002 22 babies (7 days < 1 year) died, which means 0.11 per 1000.** Since we do not know yet the figures of the categories related to SIDS/cot death (acute respiratory tract infections, pneumonia and influenza; bronchitis; cause or death unknown or indefinite; suffocating by food; accidental suffocating in cot or bed) it is to early to make definite conclusions: it might be a matter of classification.

As you probably have read on the German or English page on our website (if not: www.wiegedood.nl – touch button Deutsch or English) there has been in fact a long history of consensus in this country concerning the care of infants. A major role play the so called baby-well clinics, which were established over a century ago. Those institutions represent a finely woven national infant welfare system, offering parents a low threshold admittance to care, information and advice; traditionally it's there vaccinations are practised and the most important recommendations are exposed and explained.

After Prof. Dr. Guus de Jonge in 1987 had come to the conclusion concerning the prone position he relatively easy could change the prevailing recommendation of prone sleep in it's opposite by instructing the baby well clinics. As a result the 'back to sleep campaign' started from there.

Today the key factors are, we believe, first emphasis on epidemiologically found risk factors and translation of the findings into preventive recommendations, then the establishment of a **National Consensus on the Prevention of Cot Death (1996)** amongst all medical disciplines and utilisation of the finely woven national infant welfare system, and finally the work of the Dutch Foundation in spreading knowledge about cot death through various communication and marketing channels. In 1996 parents, medical doctors and other specialists active in the **Dutch parents organisation since 1981**, established the **Stichting Onderzoek en Preventie Zuigelingensterfte**, or **Stichting Wiegendoed** for short. In English: **Foundation for the Study and Prevention of Infant Mortality**, shortly **Cot Death Foundation**. In the board (= the executive) parents can be represented, but volunteer members are mainly recruited for their achievements in different disciplines such as research, prevention, information, public relations, professional education and fund raising.

The office is run by the honorary secretary (= your present correspondent = a newspaper journalist and a.o. former president of the Dutch Journalist's Association = the only 'parent' so far). The

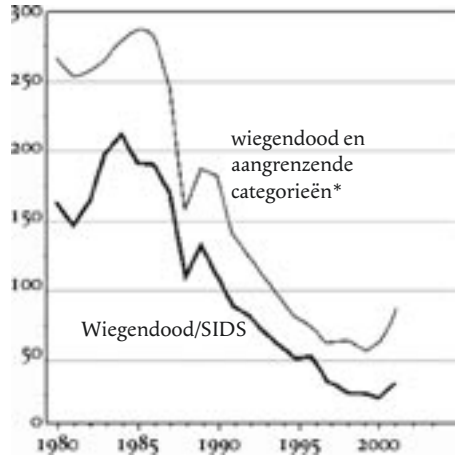


Abb. 1

Postperinatale sterfte aan wiegendoed en aangrenzende categorieën in Nederland 1980–2001 in aantallen gevallen

* aangrenzende categorieën:

- acute luchtweginfecties
- longontsteking
- algemene symptomen
- diagnose onbekend of vaag
- stikken door voedsel

foundation supports the parents organisation, which concentrates on self help and support of families of babies who have died suddenly and unexpectedly. However we have to realise this 'fellowship' never has been very powerful. At present it's not sure the organisation will survive next year, due to declining membership and lack of managerial experience.

On the other hand six years after its establishment the Dutch Foundation for the Study and Prevention of Infant Mortality has become well known all over the country. Inspired by our will to

reduce the incidence to a minimum, we have built a small, but alert and decisive organisation, recognised as a useful source of knowledge and information. You might use the Characteristic 'catalyst'. We could hardly be more.

Though we have connections with everyone professionally interested in the subject in the country, most of the daily work is done by the office (= my home-office). We have nobody employed, no governmental financial support, our budget, gathered by exploring our personal networks, is limited to about 25 000 Euro a year. Of this money we pay a.o. the costs of the continuous study of remaining cases, carried out by a volunteering group of paediatricians. Fortunately all our leaflets are sponsored, thanks to a good (personal) relationship with the country's largest publisher of magazines. The website was designed by ourselves and the exploitation is our own responsibility.

As this is not an endurable constitution we have just decided to co-operate more closely with the national Foundation Consumers and Safety (assigned by and completely financed by the government), to which we will leave the future production and distribution of leaflets. Our foundation remains the source of knowledge and will concentrate on the promotion of research, further development of recommendations for prevention, education of professionals and support of bereaved parents. We continue the publication of background information and our website, as well as our offer of special lectures.

We are convinced it is absolutely necessary to keep our focus on prevention. Therefore drawing attention is precisely the policy we practice in The Netherlands in regards of cot death: attracting as much as attention as we can get. Both of the public and of all the professionals of various disciplines who take care of babies. **And instead of scaring people with an alarming message we have come to the conclusion that it is wiser to promote a positive slogan: Safe Sleeping for your baby instead of Reducing the Risks.**

Our major prevention project over the years is called Safe Sleeping (Veilig Slapen): and it is implemented through the distribution of leaflets containing a range of recommendations to reduce the risks of sudden infant death. Today those leaflets are published in Dutch as well as in Turkish/Dutch, Moroccan/Dutch and English. A German edition is available in DTP. All issues can be read on the website. Safe Sleeping is geared to the specific situation in the Netherlands. In 1987 already a back to sleep campaign was launched. In 1995 the international study European Concerted Action on SIDS (ECAS) drew maximum attention to cot death in our country. And in 1996 a National Consensus on Prevention of Cot Death was agreed upon by virtually all professional organisations involved in baby care.

In the past five years our message has been widely spread by coloured leaflets and as from April 2001 also by an accessible, conveni-

ent website (www.wiegedood.nl or www.wiegendood.nl) – easy to find and to handle, even for those with not very sophisticated, old fashioned, low speed machines. The characteristics we aimed for: Easy to find on the internet, simply to open, clearly classified, readable text with supporting illustrations, user-friendliness, no labyrinth and exit must be without obstacles.

In 1996 The Netherlands had the good fortune when the National Consensus on the Prevention of Cot Death was held. This meant that the support of all professionals of the various disciplines in medicine and childcare and their organisations was obtained. From that moment the Foundation took the opportunity to recruit many of the professionals to hand out the recommendations – in the form of our leaflets – to young or future parents. The most satisfying outcome of this set up now is our strength: our most modest foundation itself would never have been able to penetrate so deeply in the society as a whole.

In order to keep alive the subject of cot death (SIDS) and more specifically our prevention projects we publish press releases as often as we can, mostly addressed to special media like professional journals or consumer's magazines interested in babies and health, but also on our website. Sometimes we address the general media like newspapers and broadcasters. We are always seeking co-operation with useful, solid partners. For example with our partner, which

I mentioned before, the independent Dutch Foundation that is focused on consumer's safety. Before publishing issues concerning baby's safety their experts do consult our foundation.

Maintaining high standards, we have developed a wide range of approaches to medical doctors (including paediatricians of course), other professional health care workers and their organisations, media, baby goods manufacturers and the general public. Our hard core business is to inform and to educate, but each category requires its own approach. Professionals require a more specific 'one to one' communication.

Medical doctors are provided with information through scientific publications, lectures, other forms of educational transfer of knowledge and response to their questions. Remaining cases of cot death in the Netherlands are meticulously documented and employed to update accepted common knowledge. All kind of professional health care workers, such as midwives, health nurses, community nurses and maternity assistants, are provided with background information, specific training, contributions to their professional journals and by maintaining a daily and adequate information service, by phone, fax and e-mail. The website is meant to serve professionals as well as the general public.

The approach to the general public involves skills of mass communication: illustrated colourful leaflets with unambiguous recommendations. In bilingual issues we tailored them to customs of

ethnic minorities, in future we may be able to utilise their own media.

However the English issue is based on the Dutch practice and so is the German DTP-version, they might be useful to inform groups of refugees and migrants and learn Dutch intermediaries to forward the information actively.

The central message in our leaflets concentrates on the points, which are familiar to you: sleep position, overheating, bedding, room sharing, smoking, breast feeding and dummy, sedatives, regularity and adequate rest for babies.

By the way: In the past five years smoking in the presence of a baby has been reduced significantly. There has been a dramatic fall in duvet selling. The interest in breast feeding is growing again.

Especially for childcare in professional or private settings we have developed a protocol, in which we pay attention to particular measures to reduce the specific risks of young babies confronted with stress. As you probably know recent findings show stress caused by the total change of circumstances and routine.

In the next future baby good manufacturers and traders deserve our special attention. Presuming their good will to manufacture and sell safer products and in spite of the poor and sometimes misleading information retailers provide in their shops, we will not unnecessarily attack them, but instead seek their cooperation, providing them with our message, convincing them of their obligation to

contribute to more safety for babies. In the past months we have been able to create a small platform, which has lead already to a technical study of babyblankets and one set up for another test.

To conclude:

The survey above offers a clear insight in the state of SIDS in the Netherlands. I hardly could add anything to it by performing at the coming 'Deutschlandweite Expertenkonferenz', I'm afraid. Of course you are always welcome to put specific questions. I sincerely hope you will be able to organise a very successful conference and to gather all allies you need in order to achieve your (and my) aim: the further reduction of SIDS.

Kindest regards, sincerely yours,

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