

**Final report of the research project:
“Development of a Diagnostic Classification of Paediatric Endocrine Disorders”,
ESPE Sabbatical Leave Programma, 1 July to 31 October 2006**

J.M.Wit, 3 January, 2007

Applicant: Prof.dr.Jan-Maarten Wit, Professor of Paediatrics, Leiden University Medical Center, Leiden, The Netherlands

Host: Prof.dr. Michael B.Ranke, Professor of Paediatric Endocrinology, Tuebingen, Germany

1. Sabbatical project

(carried out from July 1st to October 31st, 2006)

From 1 July to 25 September 2006 I worked at home. I adapted the 12 preliminary chapters, through many subsequent versions, and made two new chapters (Adrenal and Syndromes). The separate parts with the explanatory texts were integrated into the body of the list of diagnoses, in the form of endnotes.

The lists of diagnoses were adapted to the new edition of Brook’s Clinical Pediatric Endocrinology, and the Oxford textbook of Endocrinology and Metabolism (eds Wass and Shalet). I added all ICD10 codes. In that time I had frequently email contact with Prof. Ranke, and several times with Prof. Kelnar.

I have also had an intensive email correspondence with Prof. Cheri Deal in Montreal, who has developed a diagnostic classification for her hospital. The intention was to possibly combine both classifications. After some discussion, also involving ESPE council, it was decided that this would be difficult for a number of reasons. However, Prof. Deal and I decided to comment each other’s classification, so that optimal benefit could be obtained from the experience at both sides of the ocean.

From September 25th to 30th I was in Tuebingen, where prof. Ranke and I worked intensively at the texts. All chapters were revised several times. The original subheadings of the text were simplified into three topics: synonyms, phenotype, and comments. At the end of the week we worked with Prof. Ranke’s secretary on the layout of the text, to make it most convenient for the publisher.

From 1 to 31 October 2006 I further worked on the chapters in Leiden. Prof. Herwig Frisch was very helpful in revising and extending the chapter on the CNS and the chapter on adrenal, after discussion I had with him on 30th September. On October 3rd I wrote to ESPE council members (see attachment 1), and requested whether Council would allow us to call the classification “ESPE Classification of Paediatric Endocrine Diagnoses”. We also discussed the issue of publication, and the role that ESPE would like to see for itself. After consultation of all ESPE council members, ESPE endorsed our proposal. Negotiations with the publisher and ESPE council are still running.

On October 15th I sent all chapters out to the ESPE members who were originally involved in the first version of the Diagnostic Classification, with the request to check if they would support the new edited versions of the chapters they were involved in several years ago.

The end product of the sabbatical period was a semifinal version of the classification. I attach the title page of the current version (attachment 2)

2. Post-sabbatical period

In the period from 1 November 2006 to 1 January 2007 I have received the comments from various colleagues ESPE-members on the respective chapters, and I have incorporated these. On January 2nd, 2007, the current version was sent out to the editors and to Prof. Deal for a last check. In the coming month I shall add the OMIM numbers, check the ICD10 numbers, and add explanatory texts to a few chapters where these comments are scarce.

The current time frame is that the final version of the text will be ready by the end of January 2007. Then the layout will be changed to the publisher friendly format, so that by the end of February the manuscript can hopefully be submitted.

I attach the following documents

1. Letter to ESPE Council
2. Title page, where the support of the ESPE Sabbatical Leave Programme is mentioned. Please inform me if this text format would not be according to your wishes.
3. An example of the text in its current form: chapter 3 (Puberty)

I am very grateful to the members of the ESPE Sabbatical Leave Programme for their support. Without their support the project would not have come to a positive end.

To ESPE Council
C/o Secretariat

3 October 2006

Dear colleagues,

As you know we are currently working on the final stage of a long-term project, i.e. the establishment of an ESPE Classification of Paediatric Endocrine Diagnoses. This project started with the formation of an ESPE Working Group on Diagnostic Classification in the early 1990ies. We first tried to obtain EC funding for this project, but this application unfortunately failed. Thereafter, we tried to generate the classification with the help of many ESPE members, but it soon appeared that the editorial work would still largely surpass the time available to us. Only recently, the generous support from the ESPE Sabbatical Leave Program to one of us, has made it possible to make substantial progress.

We now anticipate that the classification will be ready for submission in December 2006. It is therefore timely to discuss several formal aspects.

First, we wish to formally request ESPE council that the Diagnostic Classification that we have prepared may be called ESPE Classification of Paediatric Endocrine Diagnoses (ECPED). We have always considered this project as an ESPE activity, but with the disappearance of an official ESPE Working Group for Diagnostic Classification, there is no formal link between the project and ESPE anymore. We would be interested to hear the opinion of ESPE Council. Obviously, we will be happy to send the semi-final version of the classification to Council if this is felt needed before approval can be given.

Second, the policy with respect to publication will have to be discussed. We propose that the diagnostic classification will be published as a Hormone Research supplement, and apparently the publisher (Karger) has shown interest to make this possible. However, also other means of publication (eg, book, electronic, ESPE website) are viable options. One issue that is of importance in this context, is who will 'own' the Diagnostic Classification. There are three parties involved (ESPE, editors, and publisher) and there are certainly legal aspects that have to be clarified. We propose that a representative of Council will discuss this matter further with us and the publisher. We are happy to discuss this in person in the near future.

Third, we believe that it would be good if plans for the future would already be made. The document that we have prepared is considered by ourselves as the first of a series, that ideally should be followed by subsequent versions, similarly to other diagnostic classifications, like ICD-10. This would mean that the adoption by ESPE of the ECPED might have to signify that an ESPE Working Group should be established that shall prepare following editions after a few years, and thereafter. We believe that it would be good if young ESPE members would be involved in this, but we shall be available or advice.

Finally, we would like to suggest that we could discuss these points within the coming months. Our time schedule is to have the classification finished by December 2006, and submit it for publication then. Therefore, we would be grateful if Council would be able to communicate with us about the above questions and other aspects in the coming months.

Please send any written correspondence to the three of us. Jan-Maarten Wit will act as spokesman of the editors, and can be approached for telephone discussions (telephone 31-71-5262824 (office) or 31-71-5150430 (home)).

Kind regards,

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The European Society for Paediatric Endocrinology (ESPE)

Classification of Paediatric Endocrine Diagnoses

Version 1.0

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