TABLE OF CONTENTS

1.   INTRODUCTION

1.1 INTENTION OF THE DATABASE

The database for patients with epilepsy is a joint project of the University of Mannheim, Germany and the University of Southern Queensland, Australia.

The system offers the possibility to easily access all patient data at a local level, without the need of looking for paper files. Moreover, it allows the collection of anonymous data via the internet.
As the number of patients in the database increases, a truly evidence-based evaluation of therapy options will be possible, on the basis of up-to-date primary patient data. This should allow an objective state-of-the-art view of different epilepsies, similar to the large database of pediatric patients with oncologic diseases created in Germany.

The database has been written in English to allow international use. Text can be entered in English, German, French, Spanish, Italian and Portuguese.

The database has been developed only for this purpose, without any involvement or help from the pharmaceutical industry.

1.2 DATA SAFETY

Data safety was evaluated by the University of Mannheim and the system was approved without any objections.

2. DATA BASE

The program is started by clicking at „*START*", „*PROGRAM*", „*MEDICAL INFORMATICS EPILEPSY*," which opens the „*PATIENT CENTRE*" with the options „*PATIENT*", „*REPORTS*", „*TOOLS*" and „*HELP*".

2.1   PATIENT

The options available are „*SEARCH*" and „*ADD NEW*".

2.1.1   „SEARCH"

Allows to look for patient data already entered. Enter the patient's name (or part of it), and a list with the patients in the system with this name will appear. You can now either double click the first name, or you can click once and hit the „*SEARCH*" button again.
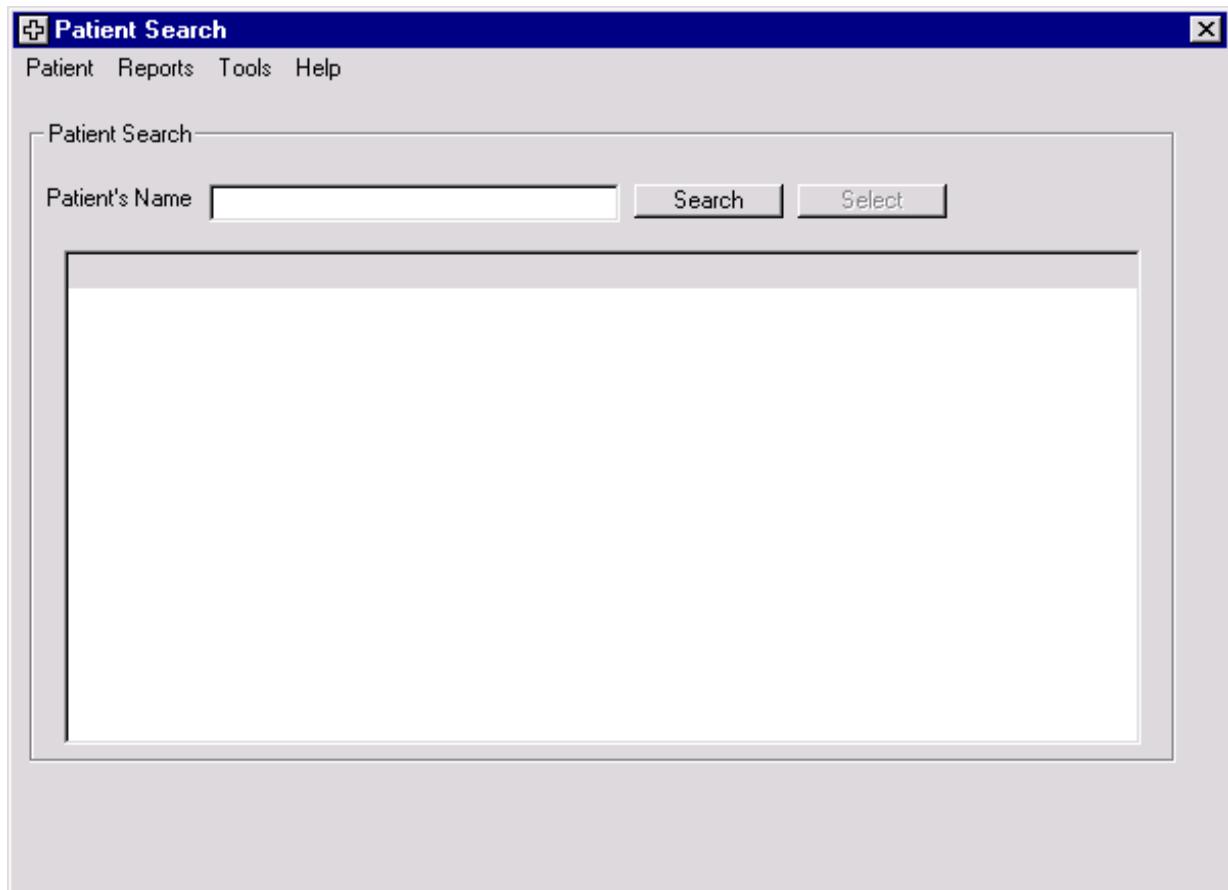
2.1.2   „ADD NEW"

In order to add a new patient, click „*ADD NEW*", the options „PATIENT, HISTORY, SEIZURE DETAILS, MEDICATION, NOTES" are offered.

A.   „PATIENT"

Enter the patient's name, address, phone number etc.

⇒   Attention: After entering one page, just click the next page (e.g. „*HISTORY*"). By clicking o.k. the data are saved but you will have to open the patient's file again. („*SEARCH*").

B.   „HISTORY"

Summarizes important facts of the history. In the categories *„AGE AT ONSET"*, *„WALKING ALONE AT"* and *„FLUENT SPEECH AT"* the zero should be replaced by the corresponding age, when saving the data a zero will be saved otherwise.

⇒   Attention : In order to delete a patient already entererd the easiest option is to over-write the data with the informtion of a new patient.

C.   „SEIZURE DETAILS"

Seizure type, frequency, duration are asked for. As to the unter „*SEIZURE CLASSIFICATION*", the seizures can be classified as „*GENERALISED*" or „*PARTIAL*". In order to correct the classification, click at „*UNCLASSIFIED SEIZURES*" and enter the correction.

D.   „MEDICATION"

In order to enter both current and former drugs choose the button *„ADD NEW".*
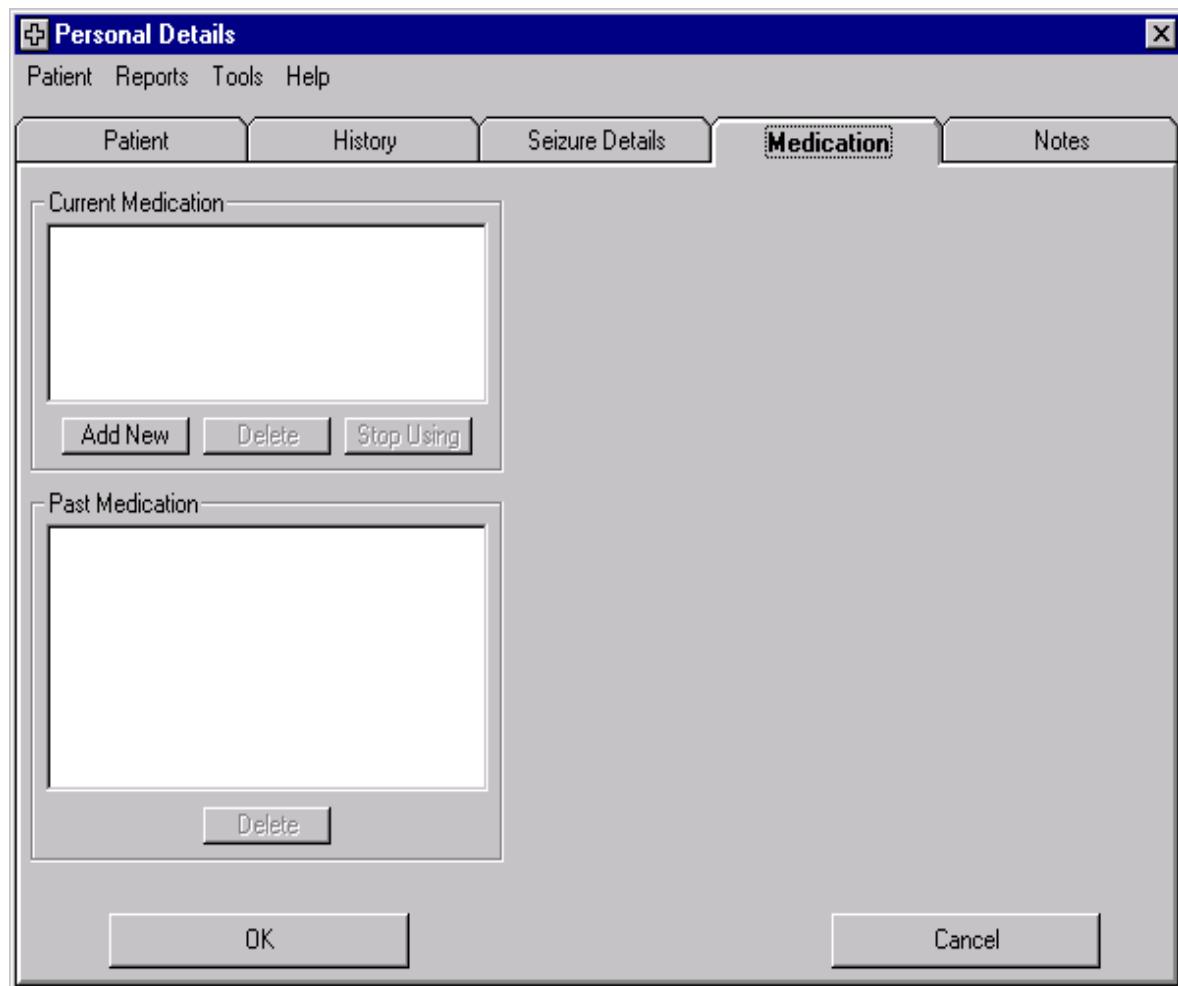
D.   „MEDICATION"

In the menu *„MEDICATION" a*nd *„DATE STARTED*" appear.
Choose the medication and enter the date when the medication
was begun and confirm with *„OK*".
Drug levels as any other more detailed information should b
estated in the *„NOTES"* section.
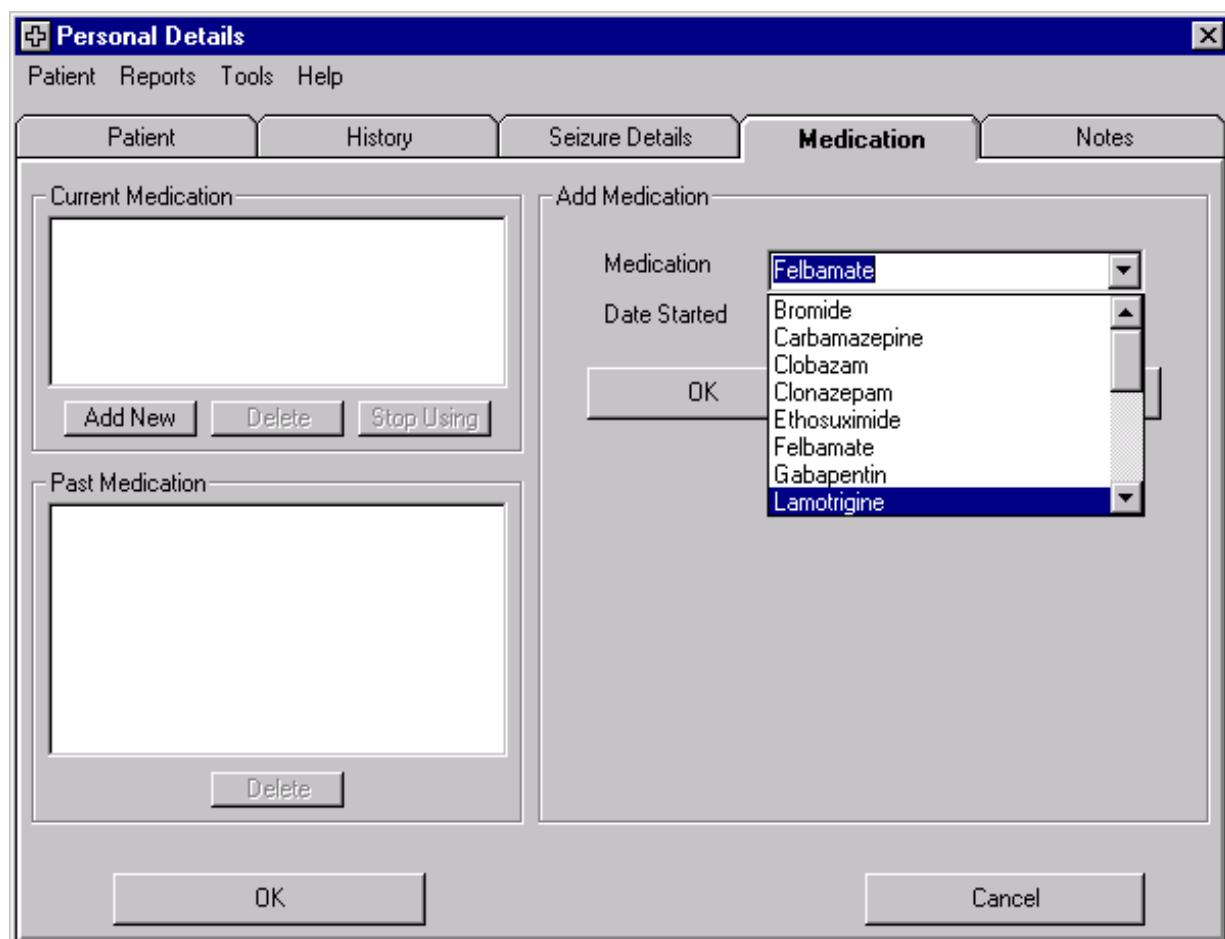
D.   „MEDICATION"

The *„SIDE EFFECTS"* button gives the common side effects of the drugs, choose by directly clicking at the side effects listed. Withdrawal of a drug can be entererd with the button *„STOP USING"*, enter the date. This will move the medication into the list of *„PAST MEDICATION". „DELETE"* is only for correction of wrong entries.
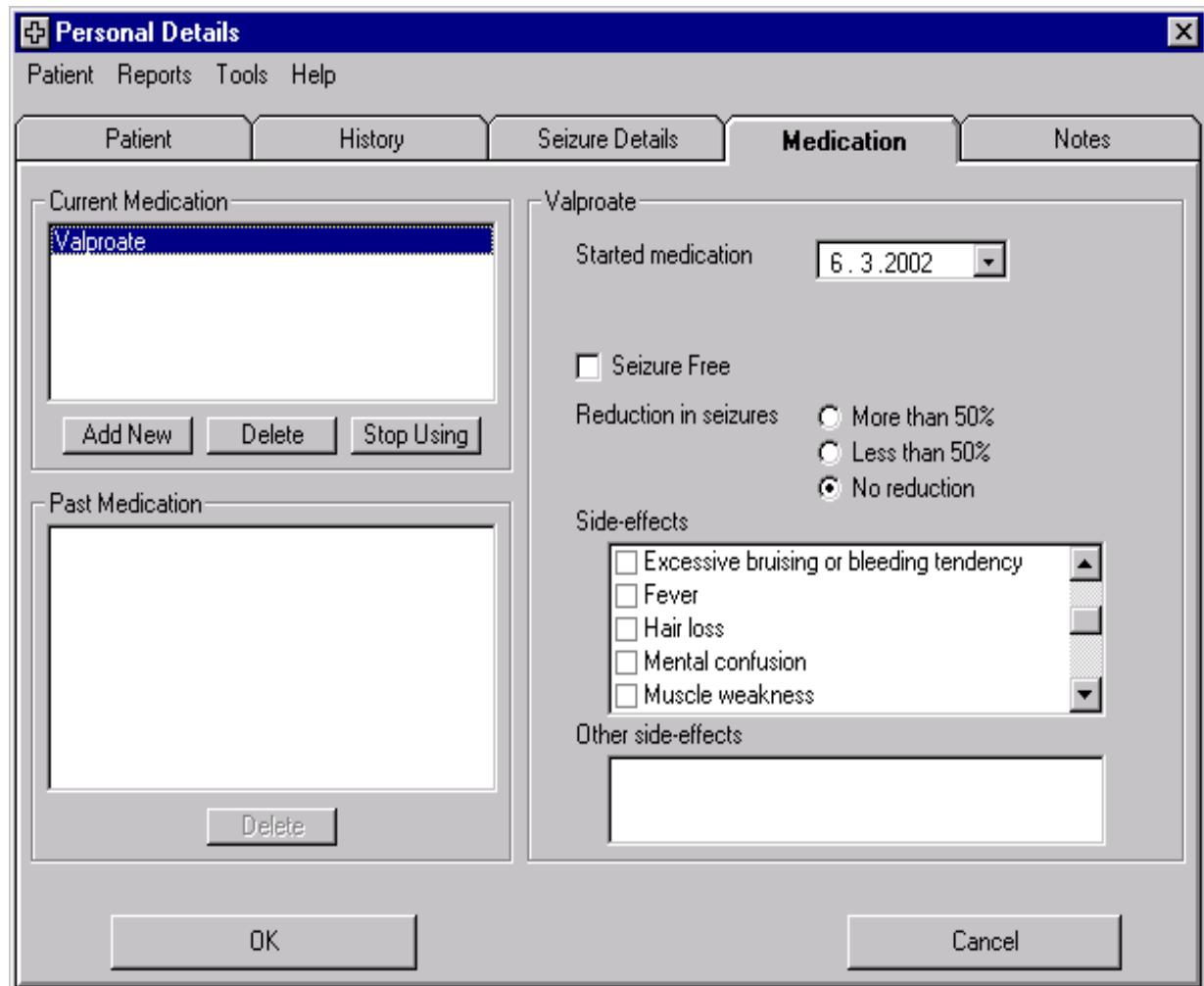
E.   „NOTES"

This is an important section, because the „click-the-Box" approach does not contain all relevant information for every patient. This is not possible, because trying to cover all possible issues would blow up the databse to at least thirty different pages which in turn would severly impede the use of the database. In the note section all important information not previously stated can be given, this section is extremely helpful when seeing a patient again. EEG-, MRT-findings, drug levels, clinical information should be gathered here.
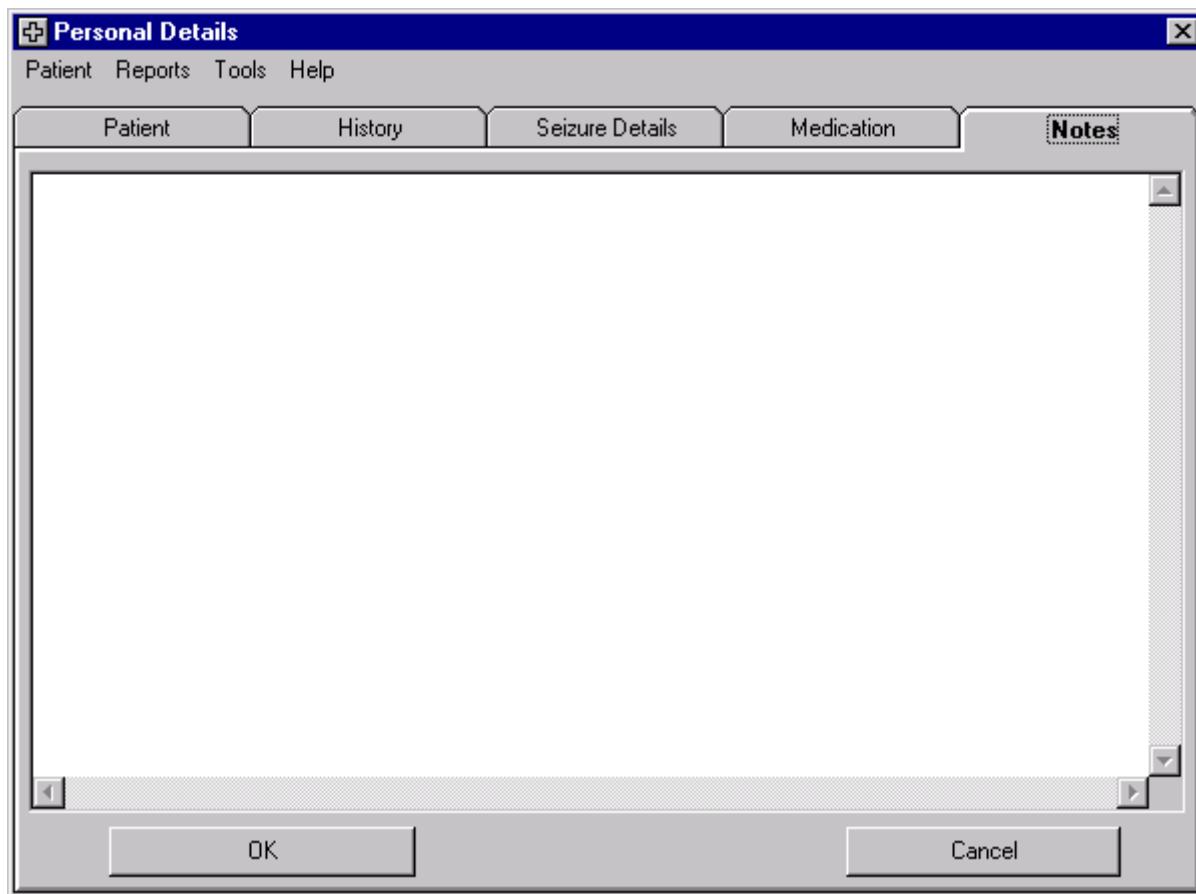
2.**2**   MENÜ „REPORTS"

The *„PATIENT LIST"* can be printed.
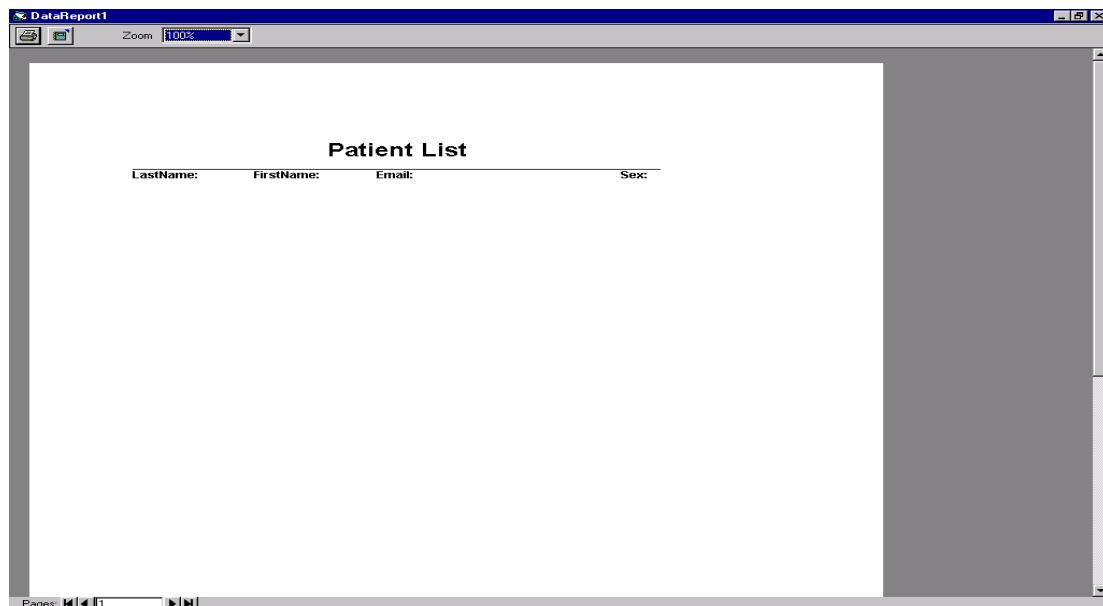
2.3   TOOLS

At *„UPDATE PERSONAL DETAILS"* you can enter your name and E-mail address.

.
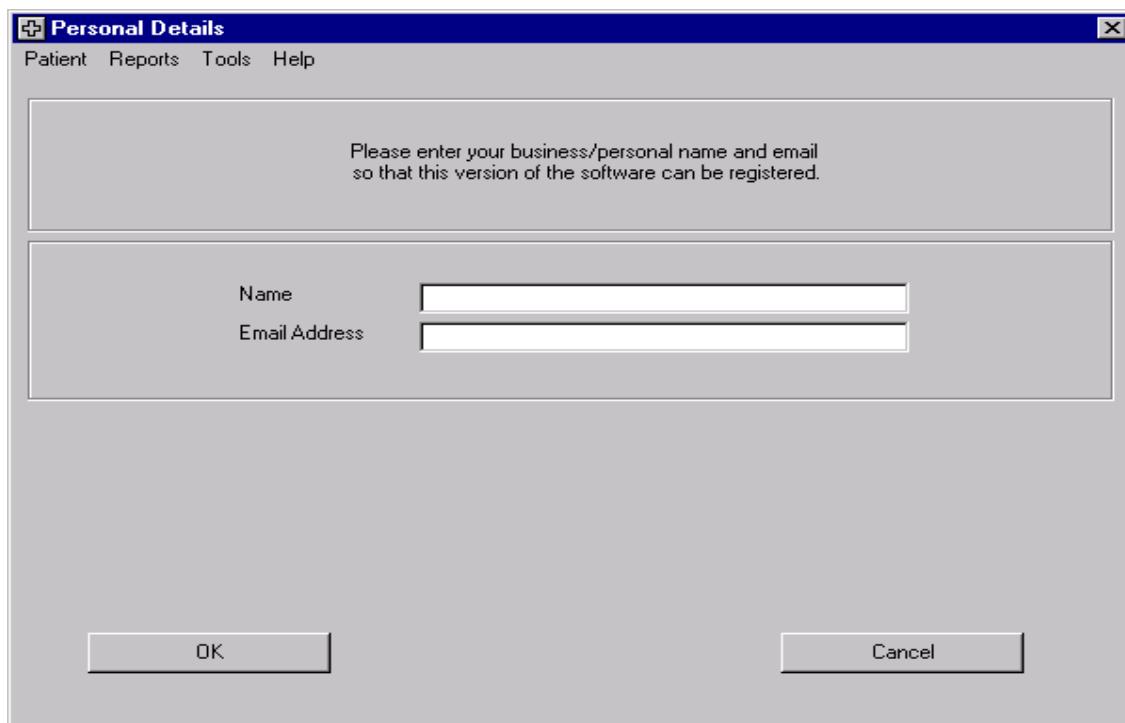
2.3   TOOLS

„*UPLOAD DATA*" allows the data transfer by a simple click. A traffic light will appear, the green light indicates the successful data tranfer of the anonymous data.

3.   DATA ANALYSIS

This option will be available within the next few months giving overall information on all patients in the system as to:

> Patients
> Seizures
> Medication
> Success of therapy related to
> Seizure/Medication
> Side effects and
> Duration of therapy

Additional reports can be obtained by directly contacting the authors.

4.   CONTACT

Drstkoenig@aol.com
elke.longin@kikli.ma.uni-heidelberg.de

5.   AUTOREN

Peter Dobson and Prof.James Taylor
University of **Southern Queensland**
Australia

PD Dr. St. König
Universitäts-Kinderklinik
Theodor-Kutzer-Ufer
68167 Mannheim
Tel: 0621/383-2243
Fax: 0621/383-2967
Drstkoenig@aol.com