

## **TABLE OF CONTENTS**

- 1. Introduction**
- 2. Database**
  - 2.1 Patient**
    - 2.1.1 Search for patients**
    - 2.1.2 New patient**
      - A. Patient data**
      - B. History**
      - C. Classification**
      - D. Medication and side effects**
      - E. Comment**
  - 2.2 Reports**
  - 2.3 Tools**
- 3. Data analysis**
- 4. Contact**

## **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*“.

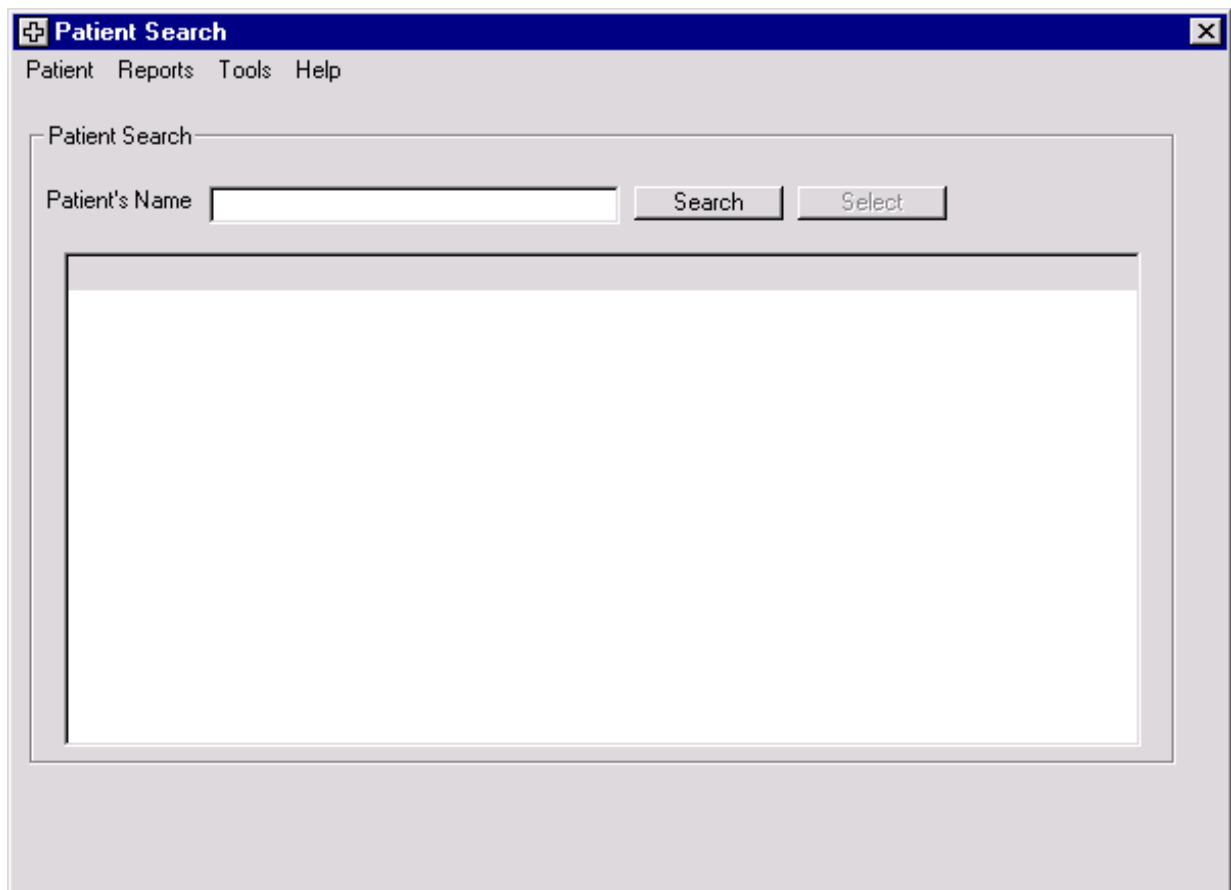


## 2.1 PATIENT

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.

The screenshot shows a software window titled "Patient Centre" with a menu bar (Patient, Reports, Tools, Help) and a tabbed interface. The "Patient" tab is active, showing two main sections: "Patient Name and Details" and "Patient Address Details".

**Patient Name and Details:**

- First Name:
- Second Name:
- Last Name:
- Birthdate:
- Sex: ☐ Male ☐ Female

**Patient Address Details:**

- Street Address:
- City/Suburb:
- State:
- Postcode:
- Country:
- Phone Number:

At the bottom of the window are "OK" and "Cancel" buttons.

⇒ 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.

**Personal Details**

Patient Reports Tools Help

Patient **History** Seizure Details Medication Notes

**Family History**

☐ Family members with seizures

Type of seizure, if known

**Epilepsy History**

Age at onset  years

Underlying disease:

☐ Tumour ☐ Malformation

☐ Head Injury ☐ Vaccination

☐ Other disease - please specify:

**EEG-Findings**

☐ Normal ☐ Focal Epilepsy ☐ Generalised Epilepsy

If known, please specify

**Patient History**

☐ Complications during pregnancy / delivery

☐ Febrile convulsions

☐ Congenital disorder

Specified:

☐ Medical problems besides epilepsy

Specified:

Walking alone at  months of age

Fluent speech at  years of age

Current School

Education

Profession

OK Cancel

⇒ Attention : In order to delete a patient already entered the easiest option is to over-write the data with the information 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.

**Personal Details** [X]

Patient Reports Tools Help

Patient History **Seizure Details** Medication Notes

**Seizure details**

Number of seizures  
0 per day

Duration of seizures  
☐ Few seconds  
☐ 30 - 60 Seconds  
☐ 1 - 9 Minutes  
☐ More than 10 minutes

Usual time of seizures  
☐ During daytime  
☐ During nights  
☐ Waking up/falling asleep

**Seizure Classification**

Generalised  
☐ Tonic-Clonic  
☐ Tonic  
☐ Clonic  
☐ Atonic (Drop attack)  
☐ Myoclonic  
☐ Myoclonic-astatic  
☐ Absence

☐ Unclassified Seizures

Partial  
☐ Psychomotor (Complex partial)  
☐ Motor signs  
☐ Somatosensory  
☐ Aura  
☐ Benign focal  
☐ Partial onset with secondary generalisation  
☐ Other :

**Syndromes**  
☐ West  
☐ Lennox-Gastult  
☐ Other :

**Are seizures favoured by**  
☐ Sleep Deprivation  
☐ Fever  
☐ Diarrhea  
☐ Television / Computer Screen  
☐ Medication / Drugs

OK Cancel

**D. „MEDICATION“**

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

The screenshot shows a software window titled "Personal Details" with a standard Windows-style title bar (minimize, maximize, close buttons). Below the title bar is a menu bar with "Patient", "Reports", "Tools", and "Help". The main area of the window is divided into five tabs: "Patient", "History", "Seizure Details", "Medication" (which is selected and highlighted with a dashed border), and "Notes".

Under the "Medication" tab, there are two main sections:

- Current Medication:** This section contains a large, empty rectangular text area for listing current medications. Below this area are three buttons: "Add New", "Delete", and "Stop Using".
- Past Medication:** This section contains a large, empty rectangular text area for listing past medications. Below this area is a single "Delete" button.

At the bottom of the window, there are two large buttons: "OK" on the left and "Cancel" on the right.



**D. „MEDICATION“**

In the menu „*MEDICATION*“ and „*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 be stated in the „*NOTES*“ section.

The screenshot shows a software window titled "Personal Details" with a menu bar containing "Patient", "Reports", "Tools", and "Help". The "Medication" tab is selected, showing five sub-tabs: "Patient", "History", "Seizure Details", "Medication", and "Notes".

On the left side, there are two sections:

- Current Medication:** A large empty text box with three buttons below it: "Add New", "Delete", and "Stop Using".
- Past Medication:** A large empty text box with a "Delete" button below it.

On the right side, the **Add Medication** section contains:

- A "Medication" dropdown menu with "Felbamate" selected. The dropdown list is open, showing the following options: Bromide, Carbamazepine, Clobazam, Clonazepam, Ethosuximide, Felbamate, Gabapentin, and Lamotrigine.
- A "Date Started" text input field.
- An "OK" button.

At the bottom of the window are two buttons: "OK" and "Cancel".

**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 entered 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.

**Personal Details**

Patient Reports Tools Help

Patient History Seizure Details **Medication** Notes

Current Medication

Valproate

Add New Delete Stop Using

Past Medication

Delete

Valproate

Started medication 6.3.2002

☐ Seizure Free

Reduction in seizures ☐ More than 50% ☐ Less than 50% ☒ No reduction

Side-effects

☐ Excessive bruising or bleeding tendency

☐ Fever

☐ Hair loss

☐ Mental confusion

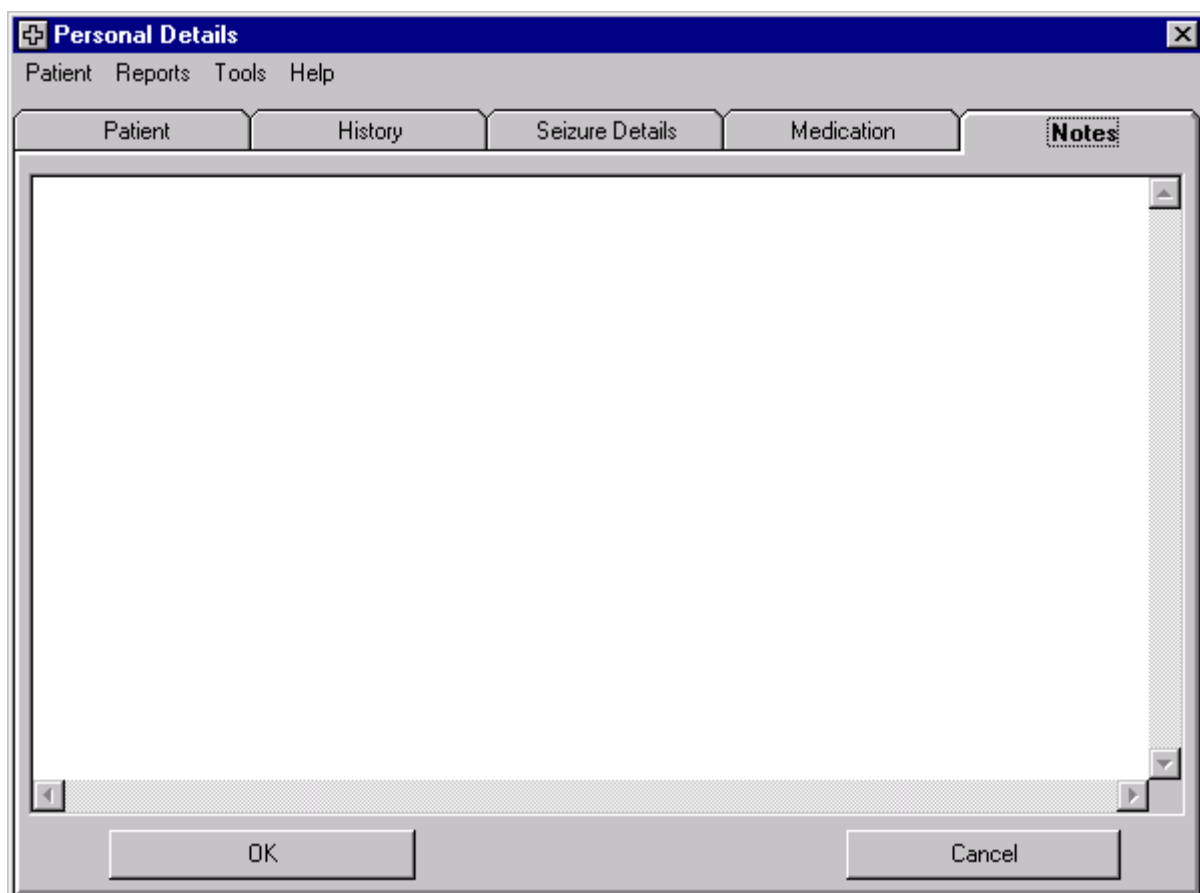
☐ Muscle weakness

Other side-effects

OK Cancel

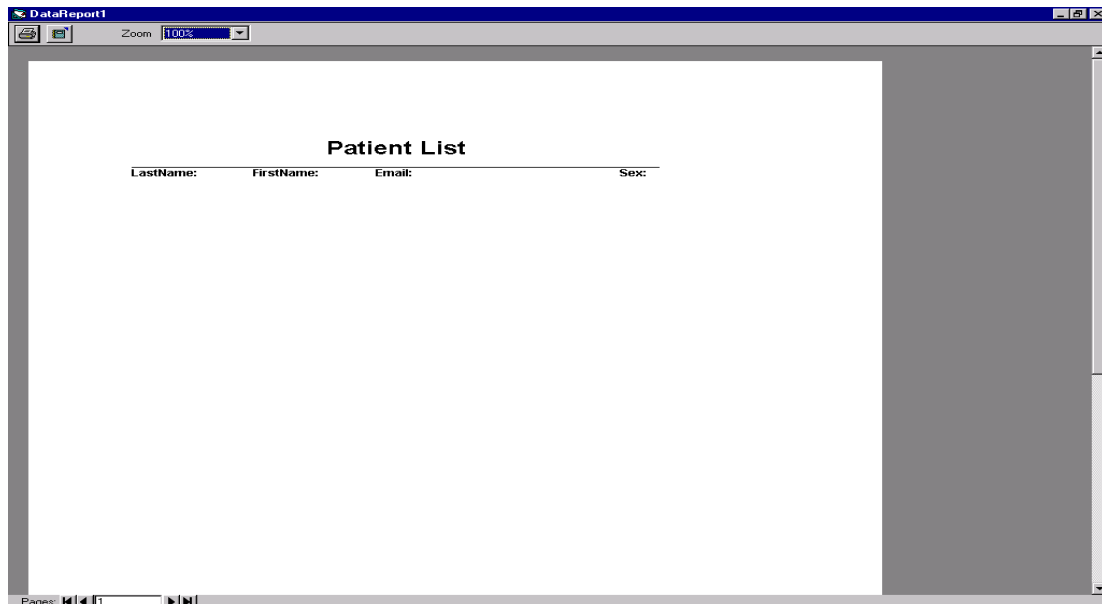
## E. „NOTES“

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 database to at least thirty different pages which in turn would severely 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.

The screenshot shows a dialog box titled "Personal Details" with a menu bar containing "Patient", "Reports", "Tools", and "Help". The main area contains a message: "Please enter your business/personal name and email so that this version of the software can be registered." Below this message are two input fields: "Name" and "Email Address". At the bottom of the dialog are "OK" and "Cancel" buttons.

## 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 transfer 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

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