The Czech Registry of Dialysis Patients (RDP)

Ivan Rychlík, František Lopot, Josef Potůček

on behalf of the Czech Society of Nephrology

Basic epidemiology data - Czech Republic 2006

- total population 10.3 mil
- 87 dialysis units
- prevalence 31.12.2006: in dialysis treatment 4,738 patients, i.e. 464 pts PMP
- total 635,774 hemopurification treatments
- peritoneal dialysis: 358 patients (7.6%)
- transplanted: 395 patients (incidence 38.3 PMP)

Registry evolution

- development started in 2004 as a project of the Czech Society of Nephrology (CSN)
- primary aims: annonymous collection of individual dialysis patients data to evaluate outcomes of dialysis treatment nation-wide, comparison of the national outcomes with similar data from abroad, comparison of specific parameters from individual collaborating centres with nation-wide means, grant-based national epidemiologic studies, evaluation of specific treatment practices onto treatment outcomes
- solely electronic means of data collection chosen to minimize the workload and to utilize the fact that over two thirds of the Czech dialysis units use the same nephrological information system (Nefris® - Nephrological Information System, devoleped by ProDos, Dobruška, CR)
- for units using the Nefris system a data exporting utility was developed, for the remaining units simplified Internet-based forms for manual filling-in was established
- data collection started in January 2006, first from the state-owned units, later Fresenius Medical Care and B. Braun Avitum chains joined

Principles

- voluntary data report
- financially supported and owned only by the CNS
- based on individual patient data report
- fully registered by state authorities
- data report quarterly (trends)
- data transfer only electronically (via protected protocol)
- electronical data protection - digital signatures and SSL authentication protocol (RSA:Digital signature algorithm; MD5-Hashing algorithm; RC4-Encrypt algorithm)
- IS NEFRIS (HD unit information system) provides per internal function quarterly-data for RDP o User friendly web based interface

Reported data

1. quarterly reported (>70 items)
2. data:
   - data of dialysis units
   - basic personal data of patient
   - periodically reported data - laboratory values (approx. the same as colleted by ERA Registry)

Outcomes

3 types of data are available:

A) current on-line data of Czech Rep.
B) back-report: dialysis unit data comparison to the mean values the Czech Rep.
C) other statistics

Data delivery:

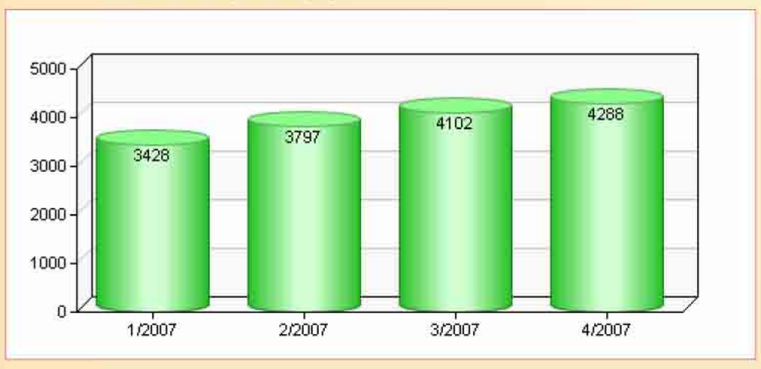
- certified all 87 Dialysis Unit (DU)
- regularly reported data of 52 DU (all data 43 DU ≥ 3x/y, partial data 9 DU 1-2x/y)
- currently registered **4485** active patients since 2006
- i.e. 49% of DU and 57 % of prevalent patients (= 6398 pts. by Statistical Yearbook CNS 2006).

A/ on-line data of Czech Republic

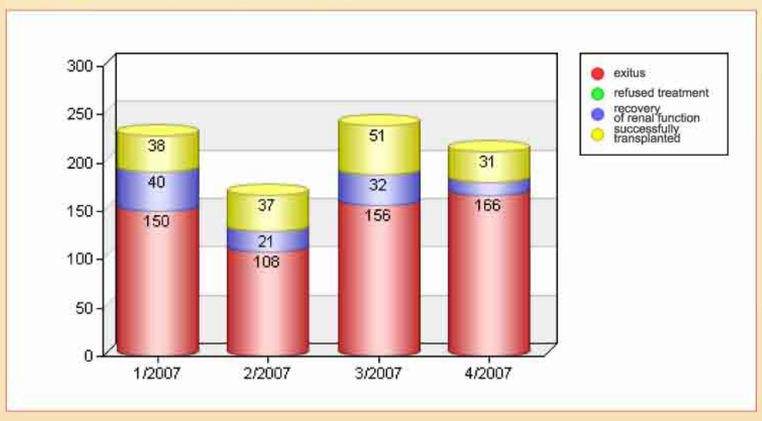
- in principle, all combinations of all registered parameters are available of 70 items registred

examples:

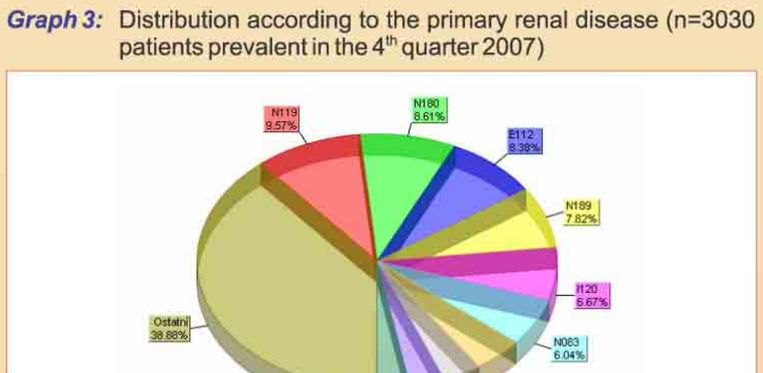
Graph 1: Patients listed as active, i.e. currently on chronic dialysis treatment (>90 days)



Graph 2: Patients registred as others



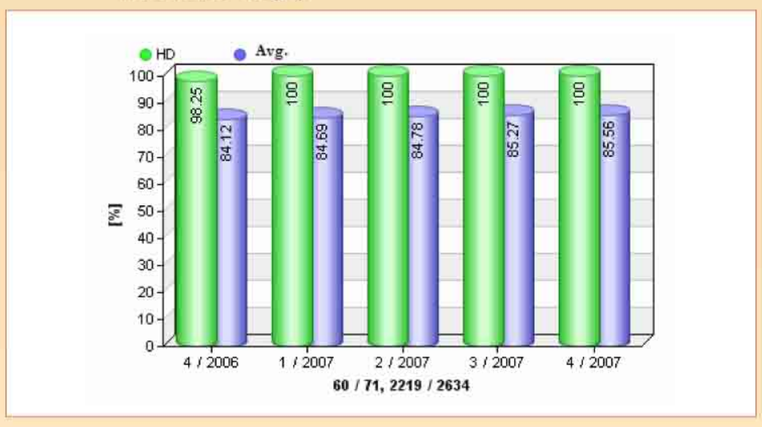
Graph 3: Distribution according to the primary renal disease (n=3030 patients prevalent in the 4th quarter 2007)



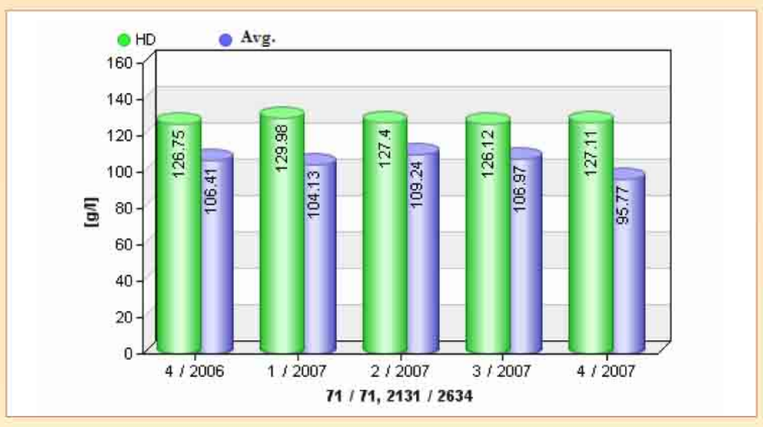
B/ back-report: dialysis unit data comparison to the mean values of the Czech Rep.

Examples:

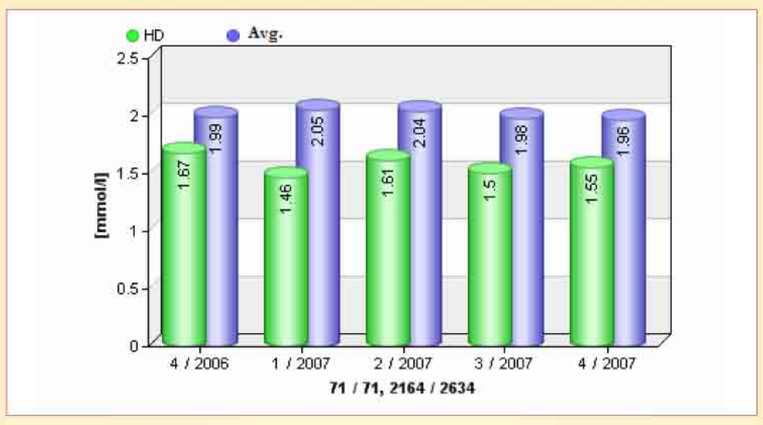
Graph 9: Percentage of patients on dialysis 3x a week (n=2219 patients; green bars: individual dialysis unit, blue bars: national average)



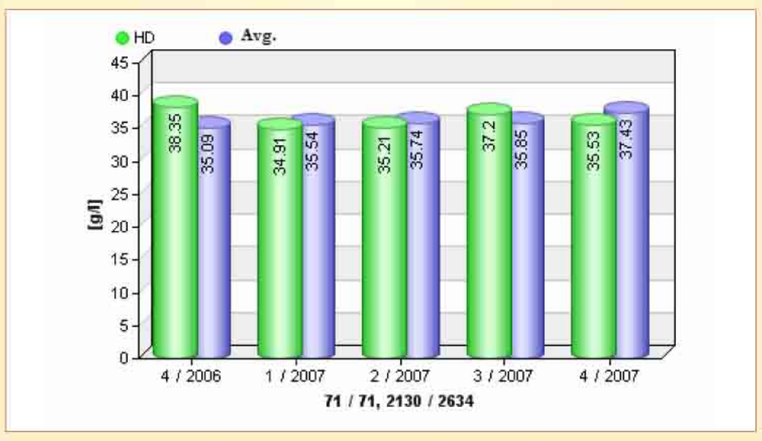
Graph 10: Mean hemoglobin values (n=2131 patients; green bars: individual dialysis unit, blue bars: national average)



Graph 11: Mean phosphate levels (n=2164 patients; green bars: individual dialysis unit, blue bars: national average)



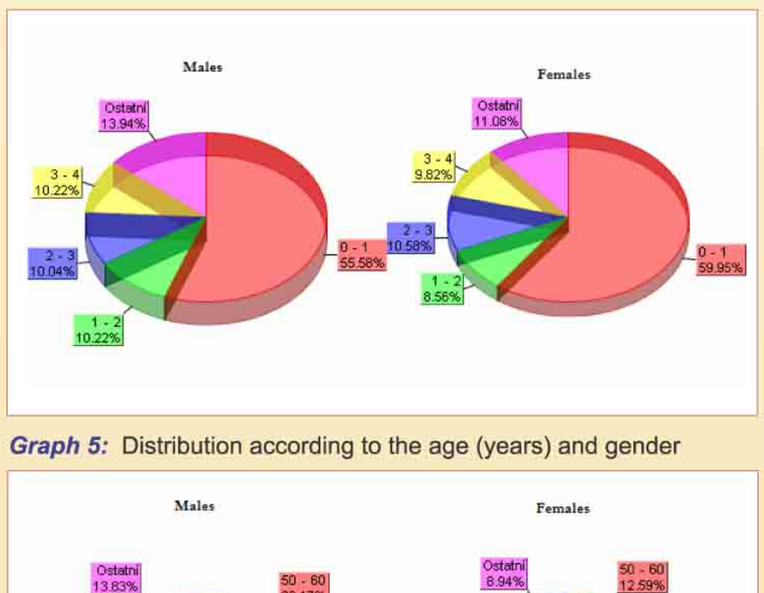
Graph 12: Mean serum albumin levels (n=2130 patients; green bars: individual dialysis unit, blue bars: national average)



Graph 4: Distribution according to the duration of RRT (years)

Graph 5: Distribution according to the age (years) and gender

Graph 6: Distribution according to the type of vascular access



Developed and supported by:

ProDos Software®
www.prodos.cz
www.nefris.com

Contacts:

rychlik@cesnet.cz
f.lopot@vfn.cz

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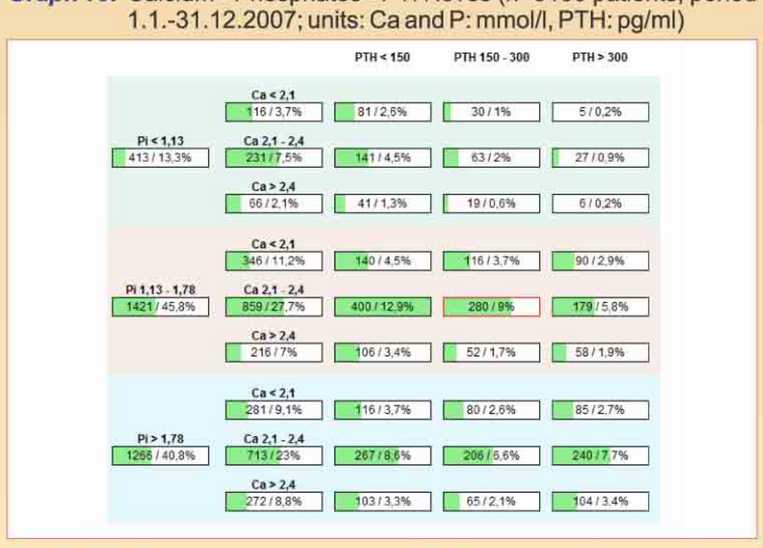
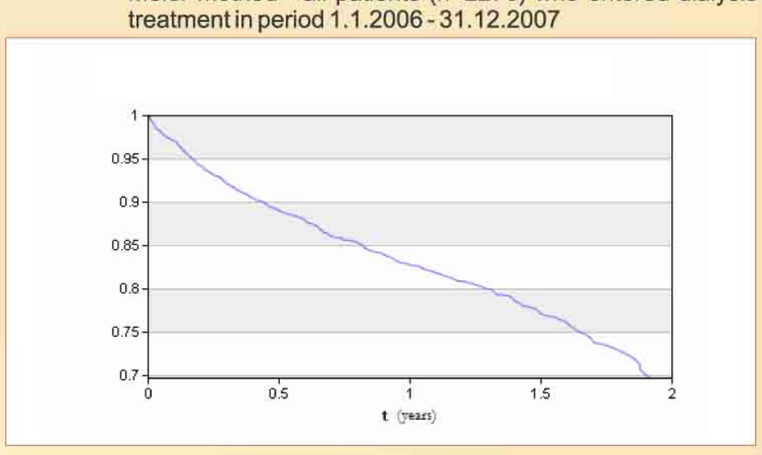
C/ examples of other statics

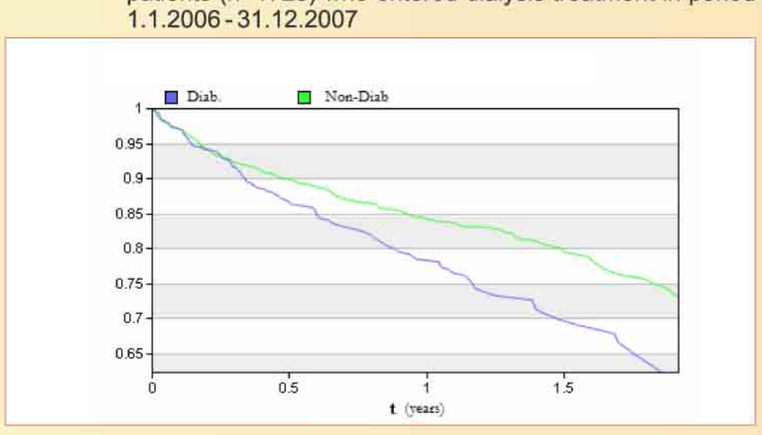
Graph 13: Calcium - Phosphates - PTH leves (n=3100 patients, period 1.1.-31.12.2007; units: Ca and P: mmol/l, PTH: pg/ml)



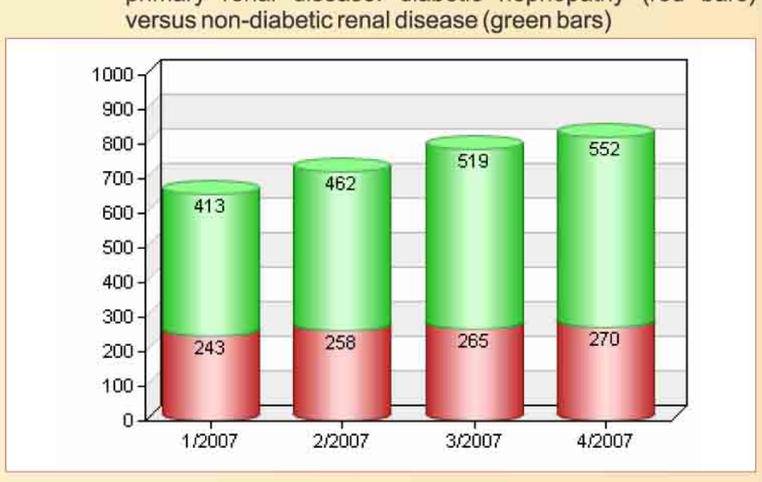
Graph 14: Cumulative survival rate: Life Table according to Kaplan-Meier method - all patients (n=2276) who entered dialysis treatment in period 1.1.2006 - 31.12.2007



Graph 15: Cumulative survival rate: Life Table according to Kaplan-Meier method - diabetic (n=548) versus non-diabetic patients (n=1728) who entered dialysis treatment in period 1.1.2006 - 31.12.2007

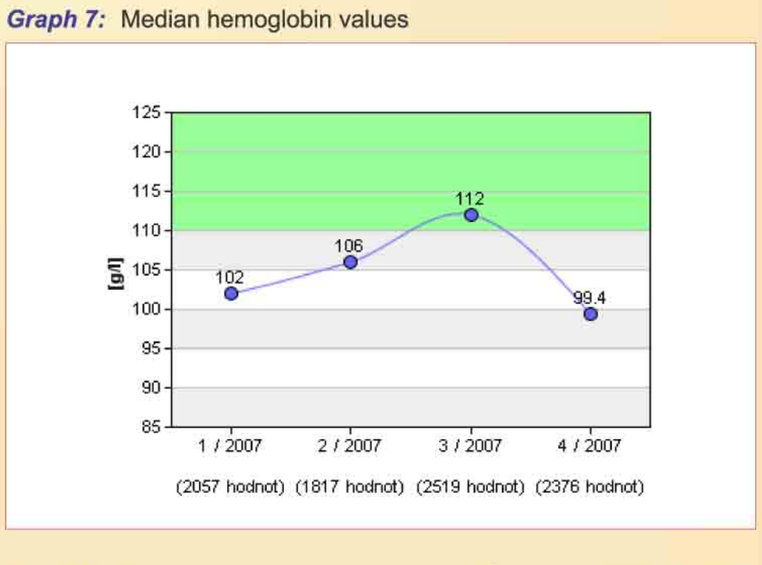


Graph 16: Numbers of diabetic patients: distribution according to primary renal disease: diabetic nephopathy (red bars) versus non-diabetic renal disease (green bars)

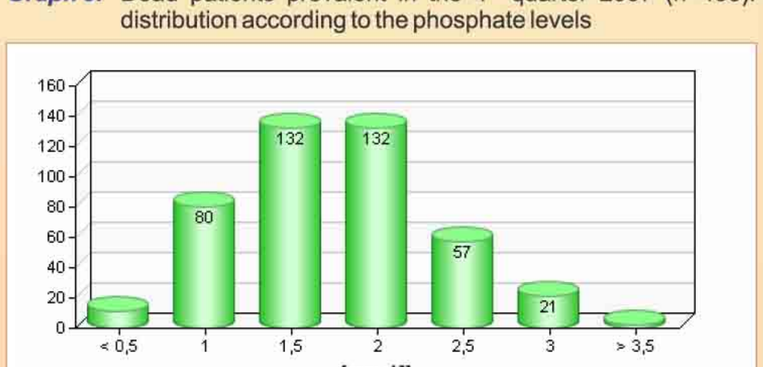


examples of laboratory values:

Graph 7: Median hemoglobin values



Graph 8: Dead patients prevalent in the 4th quarter 2007 (n=435): distribution according to the phosphate levels



Summary and conclusions

- **After 2.5 years since the start of the Registry, 52 dialysis units (60% of nation-wide count) joined, covering 69% of prevalent dialysis population in the Czech Republic**
- **Solid database with nation-wide and unit-mean values of selected patient- and treatment-related data (e.g. Hb level, Kt/V, EPO dose) created**
- **Feedback to the participating units well established**
- **The first true survival analysis (Kaplan-Meier method) performed**
- **Persisting problems in obtaining data from non-computerized units (manual filling of the Internet based forms too laborious) or from units using computer systém other than Nefris (cooperation between local IT company or system in development of an interface usually very difficult)**

Publication of annual report:

- Statistical Yearbook of Dialysis Treatment, issued by CSN (www.nefrol.cz)
- Czech RDP: www.nefro.cz:
  - public access under preparation
  - on-line data restricted only for dialysis units who reported data