The ENSAT Registry:
A digital repository supporting adrenal cancer research

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Melbourne eResearch Group
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### Adrenal Cancer

- **ACC** - Adreno-Cortical Carcinomas
- **Pheo** - Pheochromocytoma and Paraganglioma
- **NAPACA** - Non-Aldosterone Producing Adrenal Carcinomas and Adenomas
- **APA** - Aldosterone Producing Adenomas

<table>
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<tr>
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<th>Pheo</th>
<th>NAPACA</th>
<th>APA</th>
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• ENSAT
  – European Network for the Study of Adrenal Tumors

• Network started life circa. 2004

• Data distribution until 2009: CDs in the post
• Pheo: 2-8 patients per 1,000,000 of the population per year

• Same chromosomal/genetic basis for other rare diseases:
  – Disorders of Sexual Development
  – Alstrom Syndrome
  – Wolframs, Bardet Biedl

• International Symposium on Pheochromocytoma (ISP)
  – September 2011
• ENSAT-CANCER
  – FP7-funded project
  – 5 years duration, started January 2011
  – ~ €5 million

• Goals:
  – Digital linkage and harmonisation
  – Information exchange systems
  – Virtual research environment (VRE)
The Registry #1

ACC Update Surgery Record 170

**Surgery Date**
- Day: 09
- Month: Nov
- Year: 2004

**Type**
- First

**Method**

**ACC Patient Status Report**

**Record GYWU-0174**

- **ENSAT Stage:** III
- **Age at first diagnosis:** 41
- **Last follow-up:** 2006-01-04
- **Overall survival:** 2553 days (6 years)
- **Patient alive:** Yes

Patient does not have R0 resection status.

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**Back to S**

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**Patient GYWU-0174**

<p>| Case Number | Name | Diagnosis | Date | Age at Diagnosis | Last Follow-Up | Overall Survival | Status Report | Record Complete |
|-------------|------|-----------|------|------------------|----------------|------------------|--------------|----------------|-----------------|
| GYWU-0182   | Martin Fassnacht | F 1955 | National (Germany) | 2011-10-25 | 55 | Yes | Status Report | Record Complete |
| GYWU-0183   | Martin Fassnacht | M 1900 | National (Germany) | 2011-10-25 | 104 | Yes | Status Report | Record Complete |
| GYWU-0184   | Martin Fassnacht | F 1984 | National (Germany) | 2011-10-25 | 28 | Yes | Status Report | Record Complete |
| GYWU-0185   | Martin Fassnacht | M 1900 | National (Germany) | 2011-10-25 | 104 | Yes | Status Report | Record Complete |
| GYWU-0186   | Martin Fassnacht | F 1942 | National (Germany) | 2011-10-25 | 73 | Yes | Status Report | Record Complete |</p>
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- PMT
  - Prospective Monoamine-producing Tumor Study

- ADIUVO
  - Adjuvant Mitotane Therapy

- FIRSTMAPPPP
  - Malignant Progressive Pheo/Para Study

- EURINE-ACT
  - Urine steroidobolomics in ACC/NAPACA tumors

- FAMIAN
  - Imaging
Infrastructure

- Connected through IDs
  - Center: GYWU, FRPA1, GBBI, ITTU, etc
  - Patient: 1, 2, 3, 4, etc
  - Sample: TUM2, PLM3, etc
Infrastructure #2

- Google Analytics/Statcounter

- Data size
  - ~ 3000 records
  - Currently 10's of Mb transfer but imaging support may impact this

- Security
  - SSL server and client certificates issued.
  - Byte-code and SQL injection protection
  - Session protection
  - Hashed passwords and separate account database
Nightly: mysqldump → scp → gzip
Monthly: TrueCrypt for off-site backups
### Patients in Phase 1

Create New Record

Export all your patient data to CSV files

There are 251 records in this database.

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<thead>
<tr>
<th>Patient Unique Identifier</th>
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Ongoing and future work...

• Develop the security policy
  – More fine-grained authorisation control

• Develop monitoring platform
  – Who, what, when, where, why...

• Add in more data from new contributing centers
  – Padua, Berlin, Turin, Florence, Budapest
• Real cancer registry being used heavily and available for contributions…

• Ethical procedures for many countries achieved

• Accountability enforced by rigorous EU FP7 reviews

• Follow-on and support by the European Science Foundation (ESF)