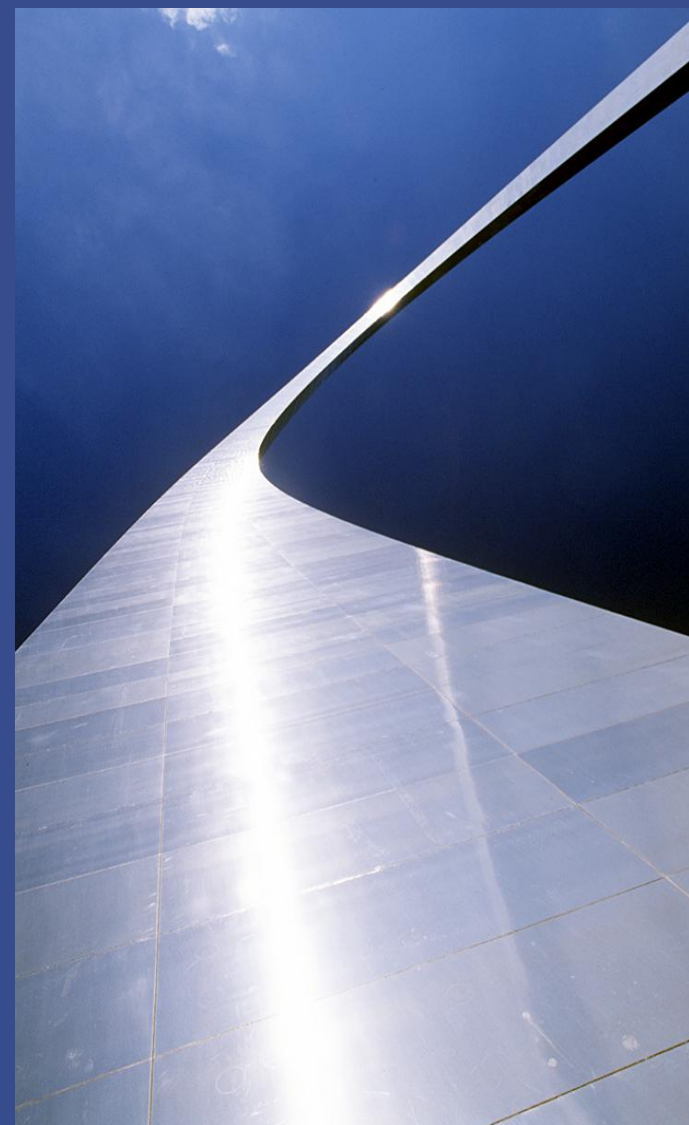




# Case Study

## Swiss PH Registry



- Pulmonary arterial hypertension (PH) is continuous high blood pressure in the pulmonary artery.
- PH is a severe disease and is often lethal by causing heart failure
- PH is an orphan disease and its diagnosis is very difficult
- 80-100 cases were assumed to exist in Switzerland
- The main therapy has a potential to cause liver damage
- It is therefore crucial to measure liver enzyme levels regularly

- The Swiss PH Registry has been designed in close collaboration with the SAPH, the Swiss group of top PH experts and the major Swiss universities
- The registry is sponsored by the manufacturer of the current “gold standard” PH therapy but open to all therapies
- User friendly internet based tool, no software installation needed
- Automatic email reminder function for liver enzyme test monitoring. Physicians are reminded repeatedly until the new liver enzyme test result is entered in the database.

Schweizerische Arbeitsgruppe für Pulmonale Hypertonie SAPH  
Swiss Group for Pulmonary Hypertension SGPH  
Gruppa Svizzera sulla Ipertensione Pulmonare GSIP  
Swiss Group for Pulmonary Hypertension SGPH

You are logged in as:  
Dr. Hanna Test, Basel, Test Country

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### Patient Data Management

Patient ID: 20030709165338XX943    Initials: DC    Date of Birth: 30.11.1935

- ▶ [New Visit](#)
- ▶ [Patient Report](#)
- ▶ [ToDo List \(all visits\)](#)
- ▶ [Informed Consent](#)

Edit Visits

Date of visit	Date of capture	Date of last change	T
09.07.2003	09.07.2003	09.07.2003	F
09.07.2003	09.07.2003	09.07.2003	B
09.07.2003	09.07.2003	09.07.2003	F

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Swiss Group for Pulmonary Hypertension SGPH

### Login

User name:

Password:

**LOGIN**

The Swiss PH Registry is an electronic registry of patients suffering from pulmonary hypertension. The Swiss PH Registry has been designed by OUTCOMES INTERNATIONAL AG in close collaboration with the Swiss Group for Pulmonary Hypertension (SGPH / SAPH / GSIP / GSIP). The development and operation of the Swiss PH Registry is sponsored by a limited grant from Astellas Pharmaceuticals Ltd. (<http://www.astellas.com>). The Swiss PH Registry is administered by the SGPH advisory board. For more information on the Swiss PH Registry, the SGPH, and pulmonary hypertension please consult the homepage of the SGPH (<http://www.saph.ch>).

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### Vital signs

Systolic blood pressure:  mmHg    Diastolic blood pressure:  mmHg    Heart rate:  bpm    Oxygen saturation:  %

Body height:  cm    Body weight:  kg    BMI:  kg/m<sup>2</sup>    Body surface:  m<sup>2</sup>

BORG:     Six minute walk test:  m    NYHA:  Class I     Class II     Class III     Class IV

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### Invasive haemodynamics

sPAP:  mmHg    Mean PAP:  mmHg    Pulmonary artery occlusion pressure:  mmHg    Right atrial pressure:  mmHg

Cardiac output:  l \* min<sup>-1</sup>    Cardiac index:  l \* min<sup>-1</sup> \* m<sup>-2</sup>    SV O<sub>2</sub>:  %    PVR:  dyn \* s \* cm<sup>-5</sup>

### Vasoreactivity test

Drug: Adenosine, Iloprost, Nitric oxide    Response:

[Top](#) | [Bottom](#)

### Add Medication

Patient ID: 20030710134320XX499    Initials: AA    Date of Birth: 02.02.1957    Gender: F    Country: Test Country

Medication

Drug class:     Drug:

Unlisted drug:

Prescription

Dosage:     Units:  / Day    Administration:     Start date: Day (dd)  Month (mm)  Year (yyyy)  Today

**ADD**    **CANCEL**



Schweizerische Arbeitsgruppe für Pulmonale Hypertonie SAPH  
Groupe Suisse sur l'Hypertension Pulmonaire GSNP  
Gruppo Svizzera sulla Ipertensione Polmonare GSIP  
Swiss Group for Pulmonary Hypertension SGPH

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## Site Statistics

Date: 09.09.2003 13:44  
User: Dr. Hanna Test, Basel, Test Country  
Country: Test Country

### Number of registered patients

City	User	Number of patients
Basel	Dr. Hanna Test	 12
Total all centers in Test Country		26
Average per center in Test Country		6.5

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- **Four times more patients registered in database than initially expected to exist in Switzerland**
- Centres participating doubled since PH registry exists
- Sponsor and experts gained surprising information about anamnesis, diagnosis, disease progression and therapy
- Gained cross centre knowledge improved diagnosis and therapy for patients
- Sponsor gained huge amount of credibility in the community of PH experts