

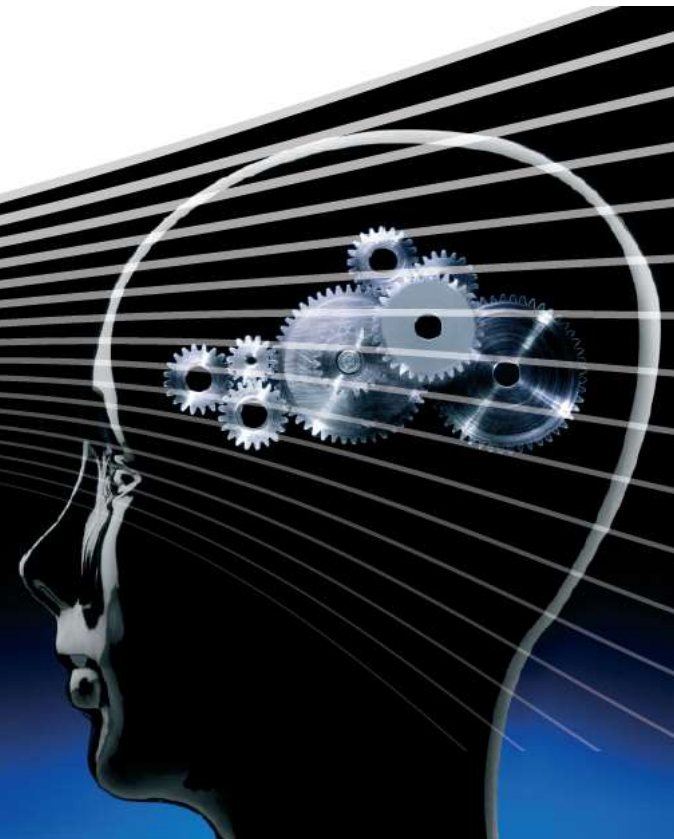
# AOSpine Tumor Knowledge Forum Biobank

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Chordoma Workshop  
March 22, 2013

knowledge  
AOSPINE FORUM

AOSpine  
Knowledge Forums



# Disclosure



**I have no financial relationships to disclose.**

# 1958 AO founded in Biel (Bienne)

November 6, 1958, Hotel Elite  
Biel (Bienne), Switzerland



# 1958 AO Founders

## Arbeitsgemeinschaft für Osteosynthesefragen



Maurice Müller

Zürich

1918-2009



Martin Allgöwer

Chur

1917-2007



Walter Bandi

Interlaken

1912-1997



Robert Schneider

Grosshöchstetten

1912-1990



Hans Willenegger

Liestal

1910-1998

# 1984 Four pillars of AO

Martin Allgöwer

Basel, Switzerland

1st AO Foundation president

Four pillars of cooperation:

- Documentation
- Teaching
- Research
- Instrumentation



## 2003 AOSpine is formed

John Webb



Nottingham,  
England

Max Aebi



Montreal,  
Canada

Paul Pavlov



Nijmegen,  
Netherlands

# AOSpine Tumor Knowledge Forum – Dec 2010





# Background & Purpose



To develop a **novel evidence-based model** with the aim of offering PST (primary spinal tumor) patients the most appropriate treatment based on the best available evidence.

## **Primary spinal column tumors (PST)**

- Rare
- Heterogeneous
- Often require surgical treatment
- Current treatment is varied
- Little high level evidence-based research to support PST management



# Material & Methods

## PST Clinical Database

### Six clinical modules:

- Demographic, diagnostic, and therapeutic data
- Two staging classifications
- Local recurrence data
- Peri-operative morbidity data
- Cross-sectional survival data

### Patient inclusion criteria:

- PST diagnosis
- Surgically treated
- At least one follow-up

### Data Capture

- Secure, web-based application
- Data was validated

The image shows a screenshot of a REDCap data capture form titled "Primary Tumor". The form is tilted and contains several sections with various input fields and checkboxes. The sections include "Patient ID", "Clinical History", "Surgical History", and "Pathology". The "Surgical History" section has a large list of checkboxes for different surgical procedures. The "Pathology" section has checkboxes for "Open Biopsy", "Frozen Section", and "Immunohistochemistry". The form is a standard data capture interface used in clinical research.



# Spine Centers

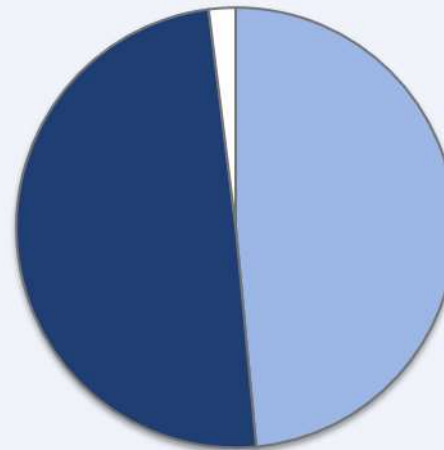
13 Sites

- 7 North America
- 5 Europe
- 1 Asia Pacific



**Total Cases:  
1,496**

**Case Distribution**

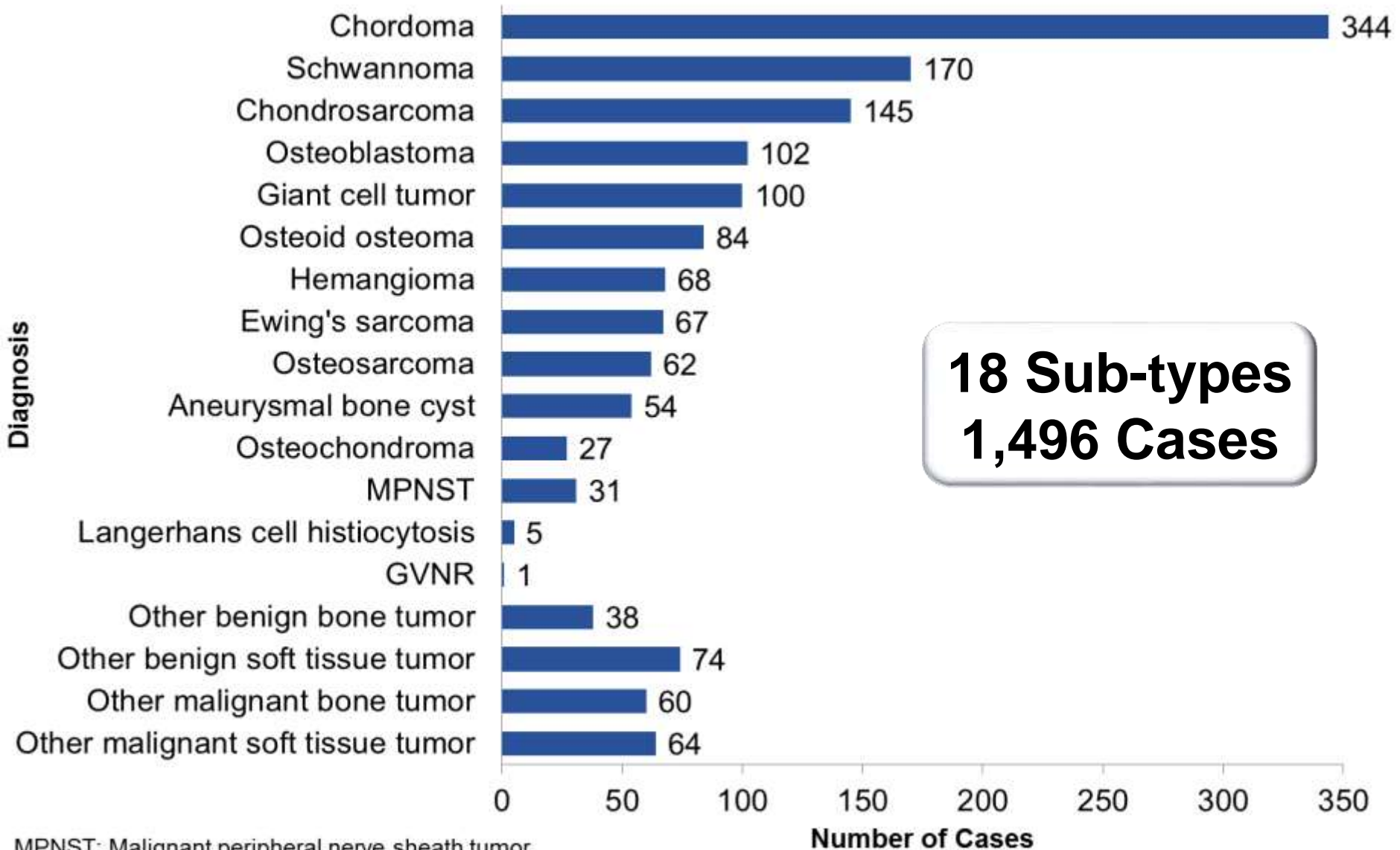


■ Europe

■ North America

□ Asia Pacific

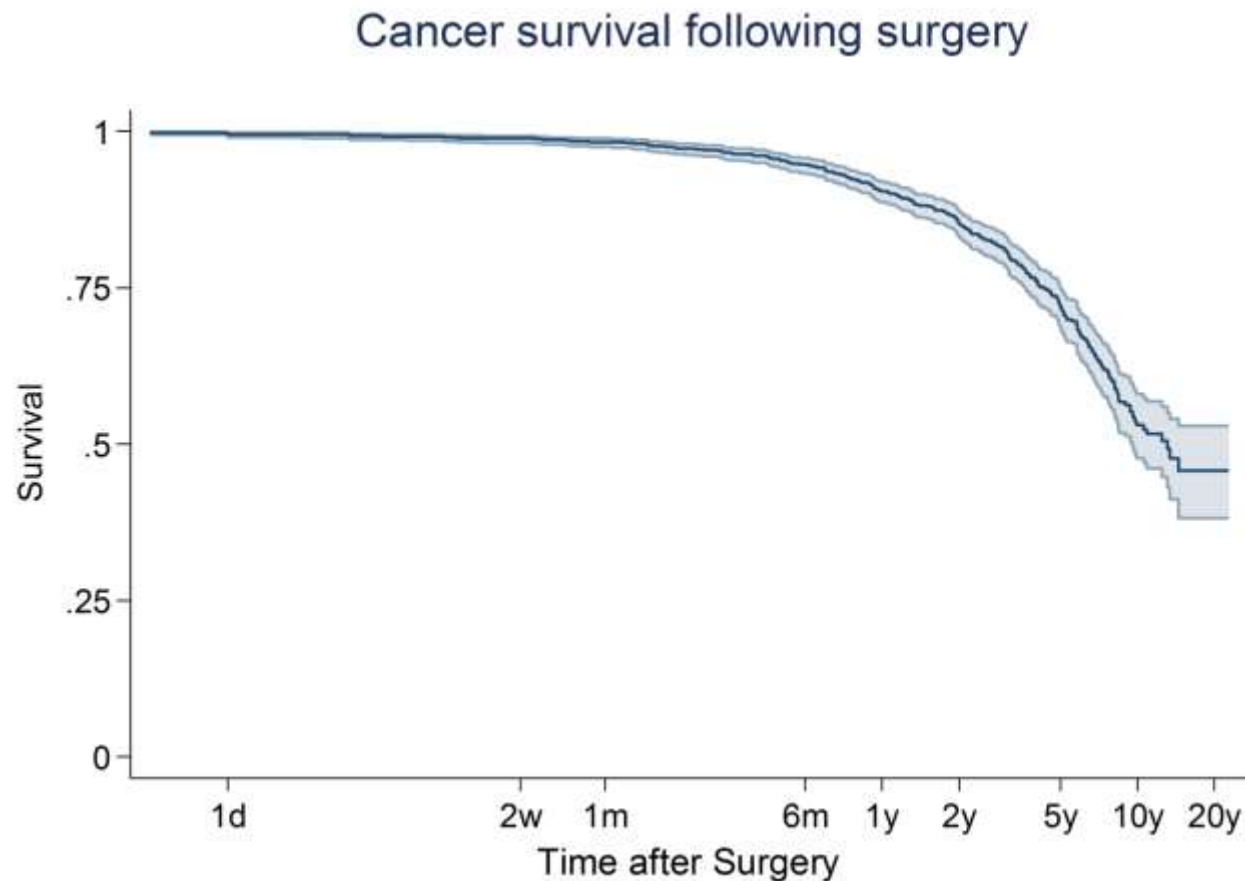
# Collection



MPNST: Malignant peripheral nerve sheath tumor  
GVNR: Giant vertebral notochordal rest

# Results

- Largest international collection of PST (675 females; 821 males).
- Mean age at time of surgery:  $43 \pm 19$  years.
- Surgical treatment was performed between 1981 to 2012.
- Survival at 5 years post-surgery is 71.9%, with a median survival of 13 years post-surgery.



# Results



- **International, multicenter collaboration**
- **Largest international collection**
  - Tumor sub-group analysis
- **Multidisciplinary**
  - Spine surgeons, pathologists, epidemiologists, etc.
  - Intra- and inter-hospital collaboration
- **Management**
  - Regular AOSpine Knowledge Forum Tumor meetings
  - Funding and support from AOSpine International
- **Retrospective → prospective collection**

# Future Directions

## Linking molecular profiles

### Retrospective collection

- To link clinical data to formalin fixed, paraffin-embedded (FFPE) tissue molecular profiles

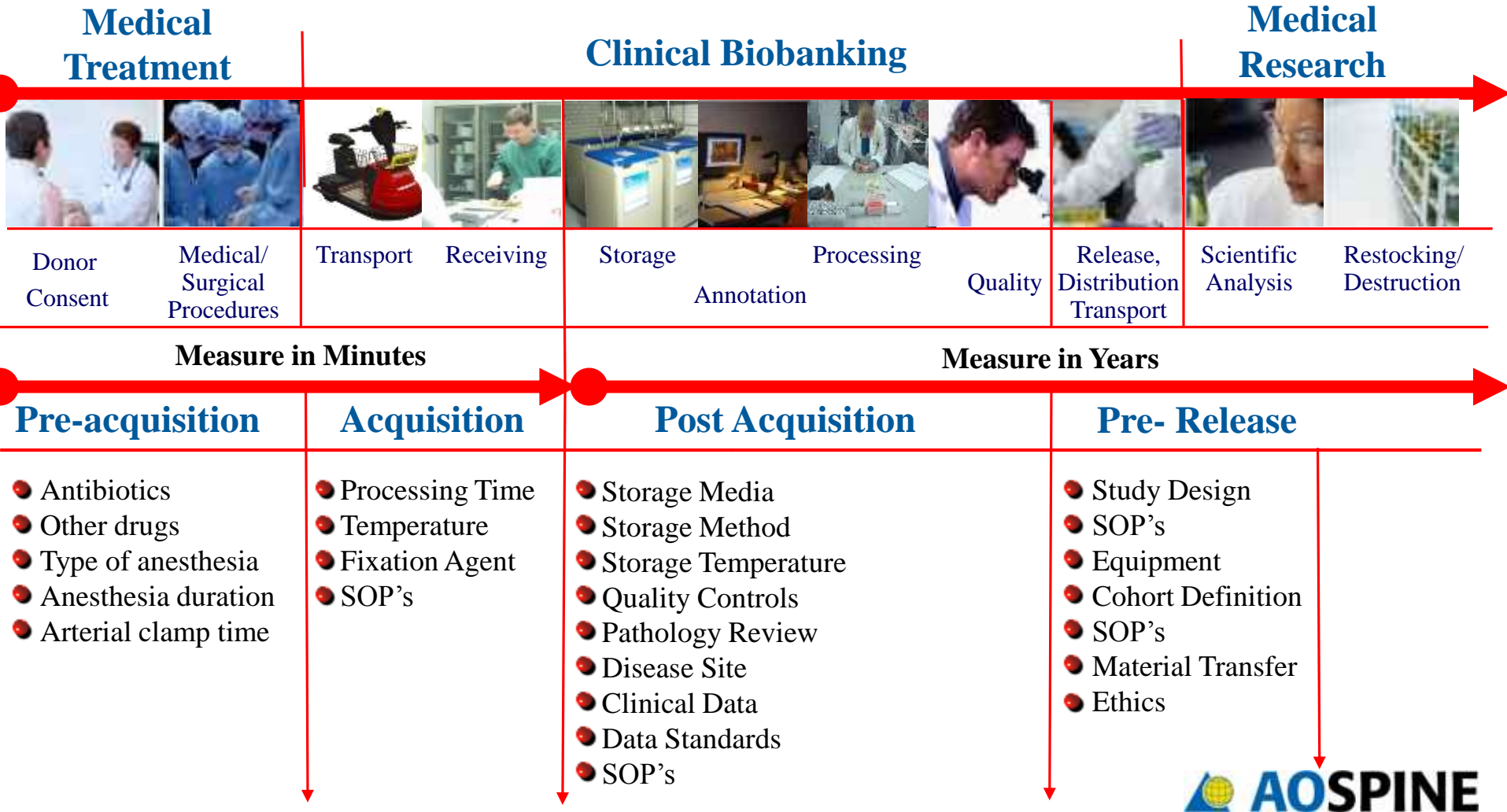
### Prospective collection (including biobanking)

- To link prospectively collected clinical data to biospecimens:
  - Fresh frozen tumor and adjacent non-tumor tissues
  - Matched blood
  - Other tissues

# PST-BioNet



*To systematically collect biospecimens and personal related data to conduct research about PSTs*





# Factors Involved in Biobanking

- Regulatory restrictions
  - Variability based on institutional, local and national regulations
  - Broad consent
  - Standardization of collection protocols
  - Obtaining high quality samples difficult (TCGA)
  - Effectively linking samples to blinded clinical data
  - Rare tumors so competing interests with local research endeavors
  - Long term funding

# Conclusions



- Largest international PST collection
- Network of spine oncology centers
- Generation of a prospective database, including the PST-BioNet
- Model for high level evidence-based research
- Can be a template for other rare neoplastic diseases

# Acknowledgements



- AOSpine International
- AOSpine Knowledge Forum Tumor
- Participating spine centers and their clinical research personnel
- AO Clinical Investigation and Documentation

