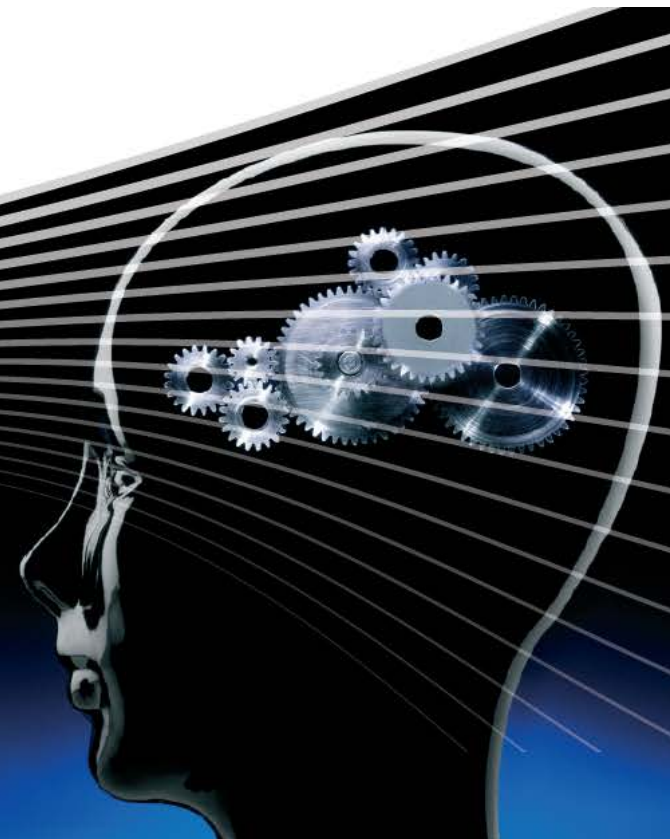


A Novel Scientific Model for Rare and Often Neglected Neoplastic Conditions

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AOSpine
Knowledge Forums



Background

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

Purpose

To develop a **novel evidence-based model** with the aim of offering PST patients the most appropriate treatment based on the best available evidence

Material & Methods

PST Clinical Database

Six clinical modules:

- Demographic, diagnostic, and therapeutic data
- Two staging classifications
- Local recurrence data
- Peri-operative morbidity data
- Survival data retrieved cross-sectionally

Patient inclusion criteria:

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

Data Capture

- Secure, web-based application
- Entered data was validated

The image shows a screenshot of a REDCap data entry form titled "Primary Tumor". The form is tilted and contains several sections for data collection:

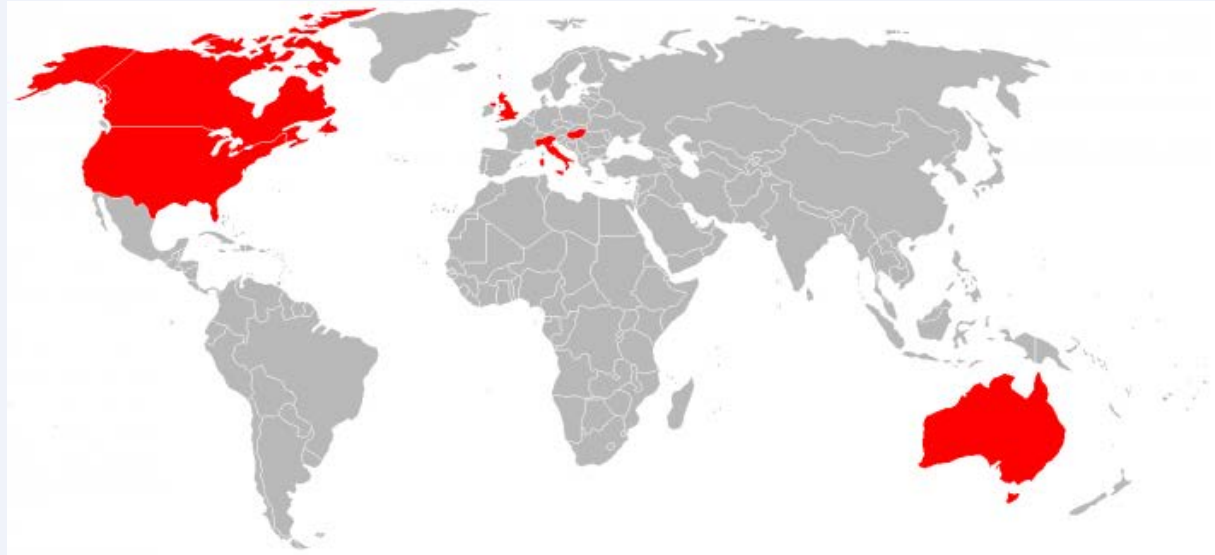
- Study ID:** A text field for entering the study identifier.
- Patient Details:** Includes fields for "Gender" (with radio buttons for Male and Female) and "DOB" (Date of Birth).
- Diagnosis Details:** Includes a "Diagnosis" field with a date format (YYYY-MM-DD) and a list of tumor types with checkboxes. The list includes: Chondroma, Chondrosarcoma, Ewing's sarcoma, Clear malignant bone tumor, Clear malignant soft tissue tumor, Clear soft tumor, Osteoid sarcoma, Hemangioma, Osteosarcoma, Osteomyeloma, Osteomyeloma with abscess, Clear vertebral metastatic lesion, Clear benign bone tumor, Schwannoma, and Clear benign soft tissue tumor.
- Other diagnosis:** A section for "Other" diagnosis with a text field and a "New Diagnosis Obtained" checkbox.
- Biopsy:** Includes a "Biopsy" section with checkboxes for "Open Biopsy", "Closed Biopsy", "Intra-operative Biopsy", and "Other", and a "Date of Biopsy Procedure" field.
- Spine Tumor Operation:** Includes a "Spine Tumor Operation" section with checkboxes for "Yes", "No", and "Not Applicable", and a "Date of Biopsy Procedure" field.



Spine Centers

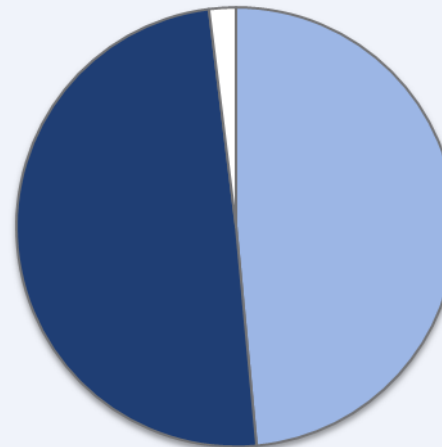
13 Centers

- 7 North America
- 5 Europe
- 1 Asia Pacific



**Total Cases:
1,495**

Case Distribution



■ Europe

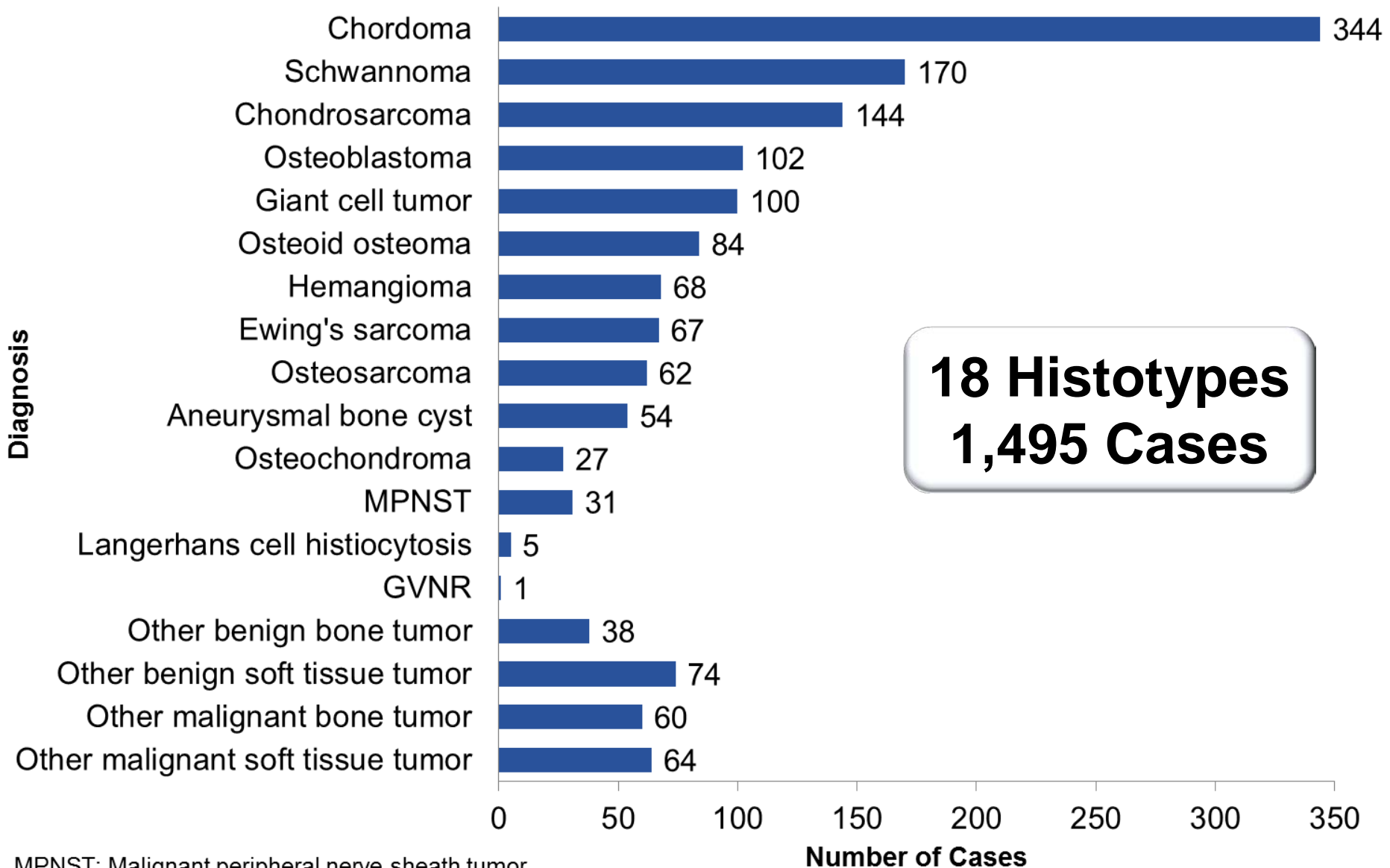
■ North America

□ Asia Pacific

Results

- **International, multicenter collaboration**
- **Multidisciplinary**
 - Spine surgeons, pathologists, epidemiologists, etc.
 - Intra- and inter-hospital collaboration
- **Largest international collection**
 - 1,495 cases (674 females; 821 males).
 - Surgical treatment was performed between 1981 to 2012.
 - Mean age at the time of surgery was 43 years (SD 19).
 - Survival at 5 years post-surgery was 71.9%, with a median survival of 13 years post-surgery.
 - Tumor histotype analyses.

Collection



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

Results



- **International, multicenter collaboration**
- **Multidisciplinary**
- **Largest international collection**
- **Management**
 - Regular AOSpine Knowledge Forum Tumor meetings
 - Funding and support from AOSpine International
- **Retrospective → prospective collection**

Future Directions

Linking molecular profiles



Retrospective collection

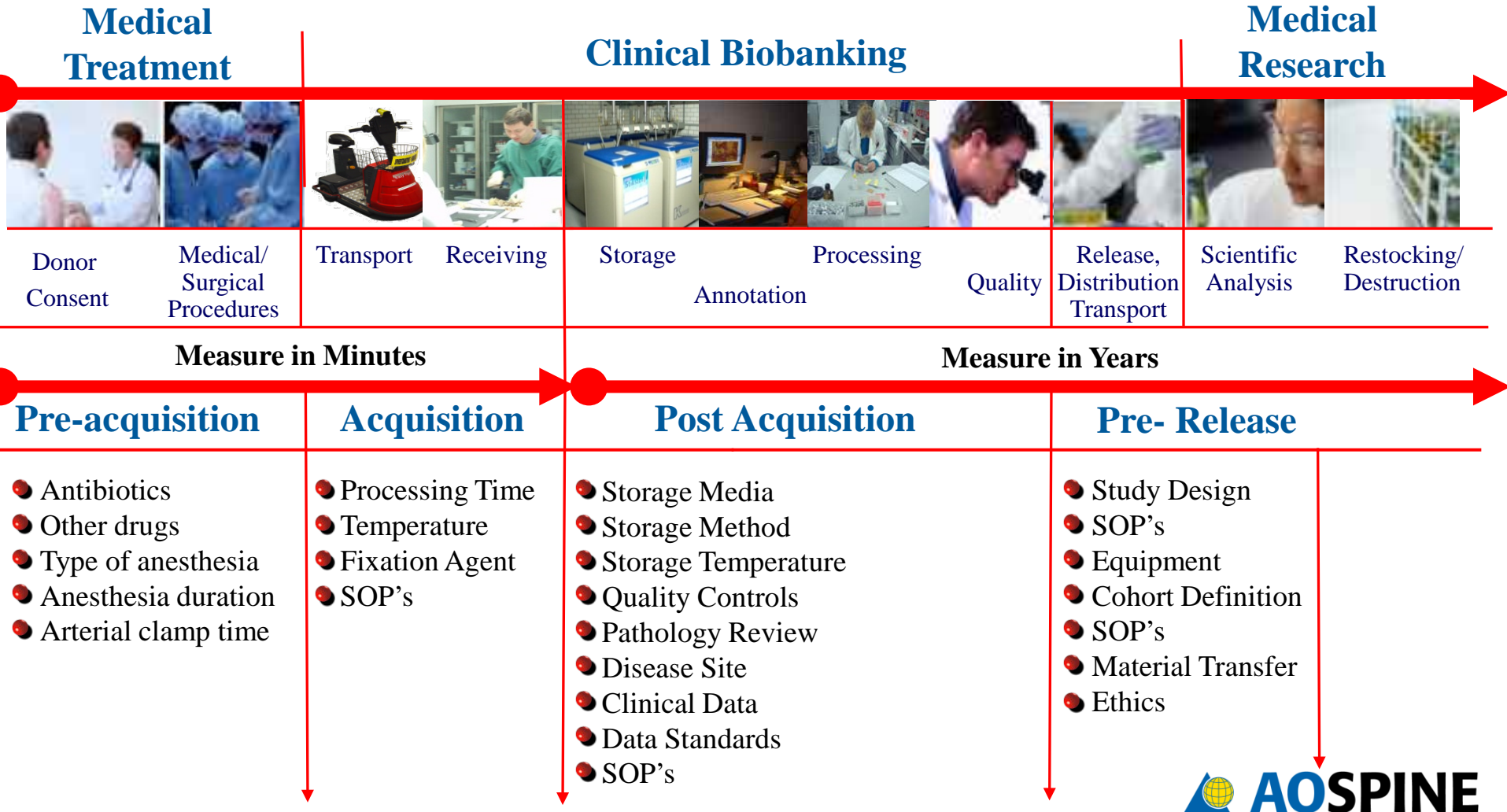
- To link clinical data to formalin fixed, paraffin-embedded tissue molecular profiles

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



Conclusions

- Largest international PST collection
- International 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
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- Participating spine centers and their research personnel
- AO Clinical Investigation and Documentation



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