Why collaborate?

For many research areas, the need to collaborate across national boundaries is absolutely necessary. This is especially the case when dealing with rare diseases where a lack of data, information and/or sharing of expertise can cause delays in progressing of the understanding and potential diagnosis/treatment of such diseases. Research into adrenal tumors is one such areas where coordination of international efforts is essential.
The Idea of “Exchange”

- Clinical, hormonal, radiological, pathological and molecular data

<table>
<thead>
<tr>
<th>Adrenocortical Carcinoma</th>
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</table>

Instructions: The Person-in-Charge Form should be completed for each TISSM patient. After completing the form, the TISSM database should be updated with the patient’s information. Questions regarding the database should be directed to the Tissue Source Site’s Data Manager. TISSM requires that all data be stored in an encrypted format.

Please note the following definitions for the “oklahoma” and “not authorized” answer options on this form.

Oklahoma: This answer option should only be selected if the TISSM has not been filled out or if efforts to obtain the information have failed. If this answer option is selected, the TISSM must complete a thorough program review and a new request for the answer is submitted.

Not Authorized: This answer option should only be selected if the TISSM does not believe that the information being requested cannot be obtained. This could be because the test is not currently performed or on the patient or the TISSM knows that the information requested is never collected.

<table>
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<tr>
<th>TISSM Source Site (CBS)</th>
<th>TISSM Identifier</th>
<th>TISSM UPCI Patient Identifier</th>
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</table>

The Idea of “Extending”

- Clinical, hormonal, radiological, pathological and molecular data

- A common procedure will be set for the optimal storage of adrenal tissue (frozen, cell culture, paraffin) in view of studying DNA, RNA, proteins and functional studies.

- ACC (adrenal cortical cancer)
  - NAPACA (non-aldosterone-producing adrenal adenoma)
  - APA (aldosterone-producing adenoma)
  - PHE/PGL (pheochromocytoma, paraganglioma)
  - Congenital Adrenal Hyperplasia

The Panamerican Network for the Study of Adrenal Tumours (PANSAT)

USA-BRAZIL database-registry (clinical and genetic data)
We hope - The PanAmerican - Network for the Study of Adrenal Tumor (PANSAT) consolidates a research center of information, promotes continuing medical education and mainly contributes to the effective and personalized treatment of patients with adrenal tumor.

Next steps:

- Implementation of PANSAT
- Bilateral agreement (UM-USP) Research + Treatment + Education
- Available financial resources

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