



**IPSO Founding Members' Congress:**  
**Charting the path forward for the global pediatric stroke community**

**Vienna, May 11-12, 2020**

**Congress Mission:** To unify the global community of professionals engaged in research and clinical care for children with cerebrovascular diseases, and chart a path forward for multinational, multidisciplinary efforts.

We aim to have a highly interactive Congress, making the most of our time together as the Founding Members of IPSO. Over two days in Vienna, Congress attendees will have multiple opportunities to share opinions, network, present research and controversial clinical cases, join committees and working groups, and identify clinical and research collaborators. Congress attendees will provide input through open discussions as well as real-time, interactive electronic surveys. In advance of the Congress, the IPSO Working Group will draft the IPSO Charter and distribute it to Congress attendees to review. Attendees will be encouraged to submit scientific abstracts for oral or poster presentation, and cases for discussion at the Clinical Controversy Symposia. Products of the Congress will include the ratified IPSO Charter, a directory of IPSO Founding Members (optional inclusion of areas of interest and contact information), "top-ten" lists of research priorities and clinical needs, and Clinical Controversy Summaries that include key references and highlights of the discussion of pitfalls and best practices. These products will be electronically distributed to the full IPSO membership upon completion of the congress.

*All are welcome to join the IPSO Working Group to provide input on the IPSO charter and organizational structure, and the Congress program.*

**Goals of the IPSO Founding Members' Congress:**

1. To foster interactions between professionals with diverse interests in pediatric cerebrovascular disease and support multi-disciplinary, international research and clinical collaborations
2. To discuss and define IPSO goals and priorities and brainstorm about how IPSO can make an impact on pediatric cerebrovascular disease worldwide
3. To finalize and ratify the IPSO charter (drafted by the IPSO working group in advance of the Congress): membership, organizational structure, and policies including potential relationships with for-profit companies (pharma and device companies)
4. To clarify the relationship between the IPSO organizational structure and the non-profit organization incorporated in the U.S. to allow for charitable donations (tax-exempt in the U.S.), and discuss the advantages/disadvantages for additional incorporation in other countries

5. To determine how IPSO can best facilitate interactions between members: through face-to-face meetings (e.g., in-person conferences), electronic interactions, research collaborations, etc.
6. To raise awareness of on-going research efforts by inviting members to share their work with an emphasis on collaborative (multi-disciplinary or multicenter) studies
7. To address urgent, clinical controversies (to be selected by the IPSO working group), create a “safe space” for sharing and discussing poor clinical outcomes (that typically go unpublished), and discuss how IPSO can best address such controversies and support clinical decision making as an organization
8. To discuss how to best engage patients and families and address their priorities: education, advocacy, and interactions with patient/family organizations

## Congress Program (Draft)

### Day 1: Monday, May 11

- 8:00A Welcome and Introductions
  - Review goals of the Congress and pre-congress work of the IPSO Working Group
- 8:15A *What do we want out of our organization?*
  - Mission & vision statements, goals and strategic priorities
  - Perspectives from representatives of different disciplines
- 8:30A *How should we be organized?*
  - Review/discuss draft organizational structure (figure on IPSO webpage: <https://internationalpediaticstroke.org/working-group/>) including relationship with “IPSO, Incorporated” (U.S. non-profit organization, 501c3) legal board of directors
  - Legal incorporation in other countries: pros/cons
  - Need for additional standing committees? Need for single-discipline councils? (For example, Neurosurgical Council, Hematology Council, Endovascular Council, etc.)
  - Financial sustainability: membership dues, conferences fees, philanthropy, corporate sponsorship; how should we engage with industry (pharma & device companies)?
- 9:00A *How should we interact?*
  - IPSO Conferences: goals of face-to-face time; frequency/location of meetings
  - Electronic Interactions: options, pros/cons
  - Research collaborations: e.g., International Pediatric Stroke Study (IPSS) network, pediatric interest groups of other professional societies, other multicenter/multinational collaborations
  - Brainstorming on other ways to interact and collaborate
  - Multinational funding applications
- 9:45A Coffee break & networking by posters
- 10:30A *Clinical controversy #1* (to be determined by IPSO Working Group) 90 min
  - State of the literature: evidence supporting both sides of the controversy, and what is missing from the literature
  - Pitfalls and cautionary tales: presentation of controversial cases that we should all learn from (but rarely get published)
  - Best practices: Where do we have consensus? Where do we have equipoise?
  - How can IPSO help to address this controversy as an organization?
- 12:00 Lunch
- 1:30P Scientific Abstract Presentations #1 – short snappers 10 min + 5 questions
- 3:00P Coffee break & networking by posters
- 3:30P *Clinical controversy #2* (TBD by IPSO Working Group; same format) 90 min
- 5:00P Summary of key points from Day 1 and modifications of the draft IPSO Charter
- 5:30P Wine & networking by posters
- 7:00P IPSO Founding Members Dinner

## Day 2: Tuesday, May 12

- 8:00A Welcome to Congress Day 2: goals of the day
- 8:05A *What role should IPSO play in professional education?*
  - Clinical consensus building and dissemination
  - Ensuring future generations of pediatric stroke professionals: training opportunities and mentorship
- 8:30A *How should IPSO engage the lay public?*
  - Engaging with patient/family organizations
  - Advocacy and public health
  - Public awareness and education (e.g., Pediatric FAST)
- 9:00A Scientific Abstract Presentations #2– short snappers 10 min + 5 questions
- 10:00A Coffee break & sign-up for IPSO Committees
- 10:30A *Clinical Controversy #3* (TBD by IPSO working group; same format) only 60 min
- 11:30A Final review and ratification of the IPSO Charter
- 12:00 Summary of key points, decisions, and action items
- 12:20P Closing remarks
- 12:30P **Congress adjourns**

**Tuesday afternoon:** Founding members may plan their own collaborative meetings, network informally, and enjoy Vienna. The Congress venue, the Imperial Riding School Hotel, has numerous spaces for informal small group gatherings.

*The joint European Stroke Organization/World Stroke Organization (ESO/WSO) conference begins in Vienna on Wednesday, May 13. (The ESO/WSO program on May 12 is by invitation only.)*