

WAPO: World Alliance of Pituitary Organizations

Independent global non-profit organization uniting pituitary patient organizations.

First meeting held in 2012, established in 2016 (Amsterdam, The Netherlands)

2019: 36 member organizations, 3 upcoming members, covering approx. 30% of global population

Global Board: Argentina, Australia, Italy, Netherlands, Russia, U.S.A.

In 2018-2019 the Board held 92 virtual meetings, lasting 73 minutes / with 4-6 attendees

Social Media presence: Facebook, Twitter, LinkedIn

Newsletter released: 4 times a year

Past Summits: Amsterdam, Netherlands (2), Venice, Italy (1), Lyon, France (1)

2020: Buenos Aires, Argentina

wapo.org



WAPO's Goals for Cushing's and other Pituitary Diseases

Ultimate goals according to WAPO 'Declaration of Zurich' (2012)

- Improve diagnostics
- Improve treatment + access to treatment & medication
- Global registration of patients per disease

ERCUSYN Study (European Society of Endocrinology)

- In 2006 → Application by a number of leading European endocrinologists to apply to the European Union (EU) call under the Public Health Program and succeeded in getting funding for 3 years (2007-2010), to set up a European Registry on Cushing's Syndrome (ERCUSYN). To date, the project has recruited information from over 1400 patients.
- Among the aims of the registry → to increase the awareness among general practitioners or primary care physicians throughout Europe, to make an earlier diagnosis, to improve the long term prognosis and “normalize” the increased morbidity and mortality associated with this syndrome if not treated correctly, to prevent the impairment in Quality of Life and to set up European guidelines for diagnosis and therapeutic strategy, etc.
- a European initiative, the European Society of Endocrinology has been a partner from the start, supporting the project in many ways.
- The database has been sponsored by the EU, ESE, Novartis, Ipsen and HRA.
- Currently ERCUSYN involves more than 59 centres from over 29 countries.

ercusyn.eu

