EDSA The early years

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The idea to create a European association on Down Syndrome, as a coordinating body between national and regional associations, arose during private conversations between Brian Stratford (Senior Lecturer, Nottingham University and adviser to the Down Syndrome Association of England), Paolo Meazzini (Professor of Clinical Psychology, University La Sapienza, Rome), Carlo Piccenna d'Aspermont (retired navy coronel and President of the Association CEPID, Catania, Italy), and Jean-Adolphe Rondal (Professor of Psycholinguistics and Scientific supervisor of the Early Intervention team of the APEM, Belgium), during a Congress organized at Catania (Hotel Baia Verde, Canizzaro), the 25, 26, and 27 of April, 1986. It was decided to take advantage of a coming international congress on Down syndrome in Europe to launch such an association.

Such an opportunity presented itself with the First European Congress on Down syndrome jointly organized by the Psycholinguistic Laboratory of the University of Liège (Direction: Professor J.A. Rondal)

and the APEM, Verviers, Liège. The event which coincided with the 10th anniversary of the Apem, took place on the campus of the University of Liège, at the Sart Tilman, from November 26 to 29, 1987.

During the congress several meetings, some informal ones, and one formal (during the evening of November 26, in the Colonster Castle of the University) let appear the possibility to create and organize an European Association devoted to Down syndrome. The idea never was to replace in any way the local associations but rather to disseminate information, motivate experts and university people, coordinate congresses and symposia activities throughout Europ, and establish contacts with the American associations.

On the eve of Friday, November 27, 1987 (at 6PM), a number of delegates gathered in the City Hall of the town of Verviers (nearby Liège) together with the Mayor of the town and several of his Assessors (Echevins) to sign a document instituting EDSA. The document had been drafted by Maître André Schoonbroodt, layer, notary, and APEM legal adviser.

EDSA FOUNDING MEMBERS

The persons having co-signed the document instituting EDSA are and have been recognized as founding members of the association.

They are in alphabetical order:

- 1. Dr. Giorgio Albertini (Rome)
- 2. Mr. Richard Bonjean (Verviers)
- 3. Mme Monique Cuilleret (Lyon)
- 4. Prof. Cliff Cunningham (Manchester)
- 5. Mr. Eric de Graaf (Zwolle)
- 6. Mme Annie Krins (Verviers)
- 7. Prof. Paolo Meazzini (Rome)
- 8. Mr. Jean-Yves Perchat (Paris)
- 9. Prof. Juan Perera (Palma de Mallorca)
- 10. Mr. Carlo Piccenna (Catania)
- 11. Prof. Miguel Puyuelo (Barcelona)
- 12. Prof. Jean-Adolphe Rondal (Liège)
- 13. Prof. Brian Stratford (Nottingham)
- 14. Mme Maria Troncoso (Santander)
- 15. Mme Montserrat Trueta (Barcelona)

Therefore 15 founding members representing associations in six European countries. At the Colonster meeting, on the eve of November 26, Carlo Piccenna d'Aspermont was elected as the first EDSA president, together with three Vice-Presidents (B. Stratford, P. Meazzini, and J.A. Rondal) also in charge of scientific matters. A General Secretary and Treasurer was appointed in the name of Richard Bonjean and the official site of the association was defined as being located in Belgium.

The Bylaws

There was no time during the Liège Congress to

draft, discuss, and vote the necessary bylaws for the association; only preliminary oral rules were discussed and approved as to the global functioning of EDSA. It was decided that the EDSA board would work together with Maître Schoonbroodt in order to propose and have the bylaws of the association adopted as soon as possible.

The EDSA board was able to propose a version of the bylaws to the general assembly held in Paris (Hôpital Rotchild) in the first days of February, 1989, which was dicussed during the meeting and voted unanimously.

The EDSA bylaws were published in the Belgian Monitor in the following months (together with the erroneous indication, that the association had been created at the Paris meeting of February, 1989, which as seen is not exact).

Presidents & Co

Numerous persons have generously given of their times and competences to make the EDSA association possible and working, too numerous to be cited here (board members, scientific advisers, vice-presidents, secretary, treasurer); their names are listed in the archives of the association (deposited with the APEM offices in Heusy-Verviers, Belgium).

Following persons have held presidental responsabilities in the association. They are in order of duty:

Mr. Carlo Piccenna d'Aspermont (Catania)

Mr. Jean-Yves Perchant (Paris)

Mr. Antonio Bosio (Genova)

Mr. Jean-Yves Perchant (Paris)

Prof. Jean-Adolphe Rondal (Liège)

Prof. Juan Perera (Palma de Mallorca)

Prof. Alberto Rasore (Genova)

Mme. Cora Halder (Nuremberg).