

LETTER TO THE EDITOR

The early history of the ESID registry

Roberto Paganelli^{1,2} 

The history of the ESID registry is described with the help of original documents of the precursor EGID going back to 1994.

The extremely interesting article by Gerhard Kindle et al. (1) reporting data from the registry of the European Society for Immunodeficiencies (ESID-R) briefly mentions in the first paragraph that the ESID-R was established as a hard copy-based database in 1994 (1), and this offers me the occasion to describe more extensively the origin of the registry, whose history has not been recorded yet in full.

The European Group for Immunodeficiencies (EGID), precursor of ESID, established the EGID registry in January 1994, as part of a concerted action operating with a grant from the European Union (E.U.) (see below). The EGID had been founded in 1983 at a meeting organized in Rome (Italy) by Prof. F. Aiuti (2), and it organized six biennial meetings until, at the sixth EGID biennial meeting held in Sitges (Spain) in October 1994, it was decided for EGID to officially become ESID. By 1983, reports of two national registries from Europe had already been published (3, 4), and the World Health Organization Scientific Group on Primary Immunodeficiencies had just published its first report (5).

At the fifth EGID meeting, held in Lugano (Switzerland) in 1992, a proposal for an E.U. concerted action on primary immunodeficiencies funded by the BIOMED-I was decided with Prof. A. Fischer as coordinator. The EGID president Prof. R. Seger informed all participants of the success of the application in a newsletter of the EGID in January 1994 (Figs. S1, S2, and S3). The first goal of the concerted action was the establishment of a European Registry of Primary Immunodeficiencies, and a Working Party composed of L. Hammarstrom (Huddinge, Sweden), G. Morgan (London, UK), and myself in Rome was appointed (Fig. S4). The data were provided on paper forms similar to those used by the existing national registries and transmitted by fax or mail to Huddinge, where they were stored in a dedicated computer.

The EGID Registry Working Party reported at the Sitges meeting that >500 patients had already been entered into the registry (Fig. 1, A and B). The primary center for the collection of data was in Huddinge, with additional centers in London and Rome. The following report of the now ESID-R, published in 1998 (6), included 7,616 cases from 25 countries, and a final one based on this registry reported 9,707 patients from 26 countries (7). Soon the registry was to change into an internet-based database (8), launched in June

2004, and stored on servers of the University of Freiburg, Germany. This led to the first report in 2007 of the new ESID-R (9) on 2,386 patients from 20 countries. The change from EGID-R to ESID-R was only in the name, so it is correct to date its establishment in 1994.

For anyone interested in the history of EGID, in Fig. S5, I reproduce the poster presented at the 21st biennial meeting of the ESID held in Marseille (France) in 2024.

The path to the success of the ESID-R started even before ESID was created, and many difficulties due to the lack of present technologies were overcome with the dedicated time and efforts of researchers and physicians studying primary immunodeficiencies from all over Europe.

Online supplemental material

Supplemental material is the reproduction of original documents stored in the author's personal archive. Fig. S1 shows the front page of the newsletter of the EGID—concerted action (BIOMED-I). Fig. S2 shows a letter from Prof. R. Seger announcing the success of the EGID application to the E.U. Fig. S3 shows a letter from Prof. A. Fischer opening the newsletter of the concerted action. Fig. S4 shows goals and tasks of the EGID project with “1: To build a registry.” Fig. S5 shows a poster at the 21st biennial meeting of ESID (Marseille, 2024) on the history of EGID.

Disclosures: The author declares no competing interests exist.

Submitted: 20 November 2025

Revised: 14 January 2026

Accepted: 20 January 2026

References

1. Kindle, G., M. Alligon, M.H. Albert, M. Buckland, J.D. Edgar, B. Gathmann, S. Ghosh, A. Gkantaras, A. Nieters, C. Pignata, et al. 2025. Inborn errors of immunity: Manifestation, treatment, and outcome—an ESID registry 1994–2024 report on 30,628 patients. *J. Hum. Immun.* 1:e20250007. <https://doi.org/10.70962/jhi.20250007>
2. Aiuti, A., R. D'Amelio, I. Quinti, and P. Rossi. 2023. Editorial to the special issue “Clinical immunology in Italy, with special emphasis to primary and acquired immunodeficiencies: A commemorative

¹Unicamillus International Medical University Rome, Italy; ²SYNERGO, Pescara, Italy.

Correspondence to Roberto Paganelli: roberto.paganelli@unicamillus.org.

© 2026 Paganelli. This article is available under a Creative Commons License (Attribution 4.0 International, as described at <https://creativecommons.org/licenses/by/4.0/>).





**VI Meeting of the
European Group
for
Immunodeficiencies**

Sitges (Barcelona) Spain
13-16 October 1994

FINAL PROGRAMME

Sunday, October 16, 1994, 12:00 - 13:00

ORAL PRESENTATIONS IV (Cont.)

- 12:00 **PRIMARY ENGRAFTMENT OF MATERNAL LYMPHOCYTES IN SEVERE COMBINED IMMUNODEFICIENCY.**
W. Friedrich, Susanna Müller, W. Hartmann and S.F. Goldmann (Ulm, FRG)
- 12:15 **REPORT FROM THE EGID REGISTRY OF PRIMARY IMMUNODEFICIENCIES.**
Mohammad Abedi, Gareth Morgan, Roberto Paganelli and Lennart Hammarström (Huddinge, Sweden; London, England; Rome, Italy)
- 12:30 **HCV INFECTION IN PATIENTS WITH HUMORAL IMMUNODEFICIENCIES.**
I. Quinti, F. Pandolfi, R. Paganelli, Daa El Salman, R. Rosso, E. Pinter, F. Aiuti (Rome, Italy)
- 12:40 **HEPATITIS C OUTBREAK IN USES OF INTRAVENOUS IMMUNOGLOBULIN IN THE U.K.**
H. Chapel, P. Simmonds, T. Wallington, C. Healey, (Oxford, U.K.)

19

- issue in honor of Prof. Fernando Aiuti". *Biomedicines*. 11:3191. <https://doi.org/10.3390/biomedicines11123191>
3. Fasth, A. 1982. Primary immunodeficiency disorders in Sweden: Cases among children, 1974-1979. *J. Clin. Immunol.* 2:86-92. <https://doi.org/10.1007/BF00916891>
 4. Luzi, G., L. Businco, and F. Aiuti. 1983. Primary immunodeficiency syndromes in Italy: A report of the national register in children and adults. *J. Clin. Immunol.* 3:316-320. <https://doi.org/10.1007/BF00915792>
 5. Rosen, F.S., R.J. Wedgwood, F. Aiuti, M.D. Cooper, R.A. Good, L.A. Hanson, W.H. Hitzig, S. Matsumoto, M. Seligmann, J.F. Soothill, and T.A. Waldmann, 1983. Primary immunodeficiency diseases. Report prepared for the WHO by a scientific group on immunodeficiency. *Clin. Immunol. Immunopathol.* 28:450-475. [https://doi.org/10.1016/0090-1229\(83\)90112-5](https://doi.org/10.1016/0090-1229(83)90112-5)
 6. Abedi, M.R., G. Morgan, H. Gooi, R. Paganelli, N. Matamoros, and L. Hammarström. 1998. Report from the ESID registry of primary immunodeficiencies. *Mol. Immunol.* 35:645-647. [https://doi.org/10.1016/S0161-5890\(98\)90342-X](https://doi.org/10.1016/S0161-5890(98)90342-X)
 7. Abedi, M., G. Morgan, H. Gooi, R. Paganelli, N. Matamoros, and L. Hammarström. 2003. Report from the ESID registry of primary immunodeficiencies. *The Source*. February/March:8-9.
 8. Knerr, V., B. Gathmann, A.M. Eades-Perner, G. Kindle, D. Vett, D. Guzman, and B. Grimbacher. 2005. The ESID online clinical and research database. *Centr Eur. J. Immunol.* 30:99-103.
 9. ESID Registry Working Party. 2007. The European internet-based patient and research database for primary immunodeficiencies: Results 2004-06. *Clin. Exp. Immunol.* 147:306-312. <https://doi.org/10.1111/j.1365-2249.2006.03292.x>

Figure 1. **The booklet with the congress program of the 6th EGID meeting (front page Top), and the page referring to the presentation of the first EGID Registry report.** Top: Front page of the program of the sixth EGID meeting in Sitges (1994). Bottom: Program page with the report of the EGID registry.

Supplemental material

EGID-European concerted action (BIOMED I)

N E W S L E T T E R 1

January 1994

Downloaded from http://rupress.org/jhi/article-pdf/2/2/e20250248/2027216/jhi_20250248.pdf by guest on 29 March 2026

Figure S1. Front page of the newsletter of the EGID—concerted action (BIOMED-I).


 EUROPEAN GROUP FOR IMMUNODEFICIENCIES
MEETING OF THE EUROPEAN GROUP FOR IMMUNODEFICIENCIES
 Lugano, Switzerland, September 30 – October 3, 1992

President:
R. Seger

Organizing Committee:
W. Friedrich
A. Morell
R. Seger

Scientific Advisory Committee:
F. Aluti (Italy)
M. Eibl (Austria)
W. Friedrich (Germany)
C. Griscelli (France)
R. Levineky (UK)
R. Seger (Switzerland)
J. Vossen (The Netherlands)

Representatives:
M. Ablun (Yugoslavia)
F. Aluti (Italy)
E. Bernatowska (Poland)
H. Chapel (United Kingdom)
M. Eibl (Austria)
T. Espanol (Spain)
M. Farber (Belgium)
A. Fash (Sweden)
W. Friedrich (Germany)
S. Froland (Norway)
C. Griscelli (France)
Z. T. Handzel (Israel)
Z. Kadagidze (USSR)
E. Kansu (Turkey)
O. Koch (Denmark)
K. Mandalenaki-Lambrou (Greece)
L. Marodi (Hungary)
A. Palma-Carlos (Portugal)
E. Savlahti (Finland)
R. Seger (Switzerland)
S. Sigurdardottir (Iceland)
J. Vossen (The Netherlands)

January 26, 1994

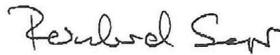
Dear Colleague
Dear Friend

As you may recall, at its last annual meeting in Lugano the European Group for Immunodeficiencies has created working parties in four important areas of research.

After an additional meeting in Zurich a grant application could be submitted to the European Community in Brussels. Today it is my great pleasure to let you know that this effort has been recognised and is financially supported.

Alain Fischer and the working party chairmen describe to you in the enclosed newsletter all planned projects. May I invite you to diffuse and support these initiatives with all your energy in order to make EGID a true European success?

Yours sincerely



Prof. Dr. R. Seger
President EGID

Scientific Secretariat
Prof. R. Seger
Univ. Children's Hospital
Steinwiesstr. 75
CH-8032 Zürich
Tel. 01/259 73 11
Fax 01/252 50 75

Administrative Secretariat
EGID
c/o AKM Congress Service
P.O. Box
CH-4005 Basel
Tel. 061/891 51 11
Fax 061/891 51 89

Bank
Union Bank of Switzerland
Zürich-Kloten
Acc. No. 821.000.11 J
(EGID 82)

Figure S2. Letter from Prof. R. Seger announcing the success of the EGID application to the E.U.

Paris, January 25th 1994

Dear Egid Member,

Eighteen european groups joined together last year to prepare a proposal for an european Concerted Action within the BIOMED Programm. This followed discussion held in Lugano during the meeting of the EGID Scientific Committee. The title of our project is :

ESTABLISHMENT OF AN EUROPEAN NETWORK FOR PREVENTION, DIAGNOSIS AND TREATMENT OF PRIMARY IMMUNODEFICIENCIES.

A PROPOSAL FROM EGID.

Our application has been granted by the european commission to a maximum of 338000 Ecus for 3 years (1994-1996). These good news provide our group with an unique opportunity to set up or to further develop collaborative studies. Every one is invited to participate to the launched studies and to propose new ones. Nobody should feel himself excluded !

You will find in this first Newsletter of our Concerted Action informations available on the Project.

Best wishes.



Alain FISCHER
Concerted action
Coordinator

Figure S3. Letter from Prof. A. Fischer opening the newsletter of the concerted action.

Year
cont
pres
MEE

p1
de

P

An informal group of ID experts already exists in the form of the European Group for Immunodeficiencies (EGID), with meetings held every two years to discuss advances in aetiology, pathogenesis, diagnosis and treatment of all above diseases. Recently EGID-Working Parties were founded to actively promote European collaborations in these areas. The present application is a direct result of this initiative. Eighteen clinical and research centers from 9 European countries will constitute the primary network necessary to achieve the objectives. They will be in connection with as many as 250 clinicians and research members of EGID throughout Europe.

3. ROLE OF PARTICIPANTS

The specific goals and tasks of this project are the following :

1) To build a registry :

(L. HAMMARSTROM, Huddinge, G. MORGAN, London, R. PAGANELLI, Roma)

The prevalence of immunodeficiency disorders varies extensively depending on the type of disease. Many of these disorders are, however, quite rare and only a few patients are expected in each country. Furthermore, multiple etiologies are likely to exist for selected diseases.

Genetic and/or therapeutic studies involve a large number of patients. Identification of patients is therefore, in most cases, a necessary prerequisite for the successful completion of these studies. Needless to say, access to a sufficiently large number of patients therefore constitutes the basis for trials and it is only by pooling the resources from all European countries that we will ultimately be able to understand the molecular basis of these disorders and to promote more efficient therapeutic measures. Usually, only a few centers in each country are referral centers for these patients which may simplify the collection of data and limited national registries already do exist. However, these registries are designed for epidemiological rather than operative purposes and access is restricted.

A Working-Party within EGID has been assigned the task to design a form which would constitute the basis for a computerized registry. The objective is to design a form which contains all pertinent types of diagnosis, easily computerized and with a simple mode of data entry and retrieval. The procedure involves the following steps :

Finalization of the registration form :

The forms will be sent to the country representatives for distribution to the various centers in each country. The data will be submitted to a center in Huddinge, Sweden where all data will be entered into a computer file. Patients identification will preserved confidentiality. Access to the data will be restricted to centers contributing data. Contact with the patients will only be allowed via the respective clinician/reporting center.

Access to data accumulated :

er

rio

ATI

ne

in

ri

Figure S4. Goals and tasks of the EGID project with "1: To build a registry."

Downloaded from http://rnpres.org/jhi/article-pdf/21/2/e20250248/2027216/jhi_20250248.pdf by guest on 29 March 2026

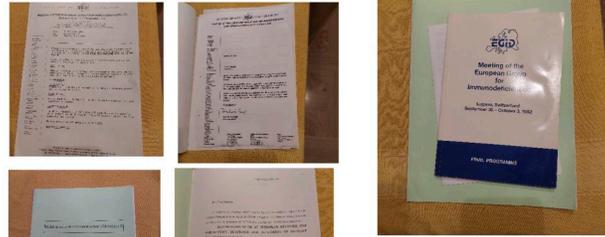
THE PREHISTORY OF THE EUROPEAN SOCIETY FOR IMMUNODEFICIENCIES (ESID)

Roberto Paganelli

Internal Medicine – Unicamillus International Medical University in Rome, Italy

The absence of archives and digitalized objects on the web concerning the long period elapsed from the first meeting of the European Group for Immunodeficiencies (EGID) and the foundation of the ESID has prompted the author to start collecting materials related to the years 1983-1994, the pre-history of the ESID. Using the word EGID very little information is retrieved in Google, so I looked for EGID publications and other information in my personal collection.

The idea of a group of interest among European scientist in the field of primary immunodeficiencies originated by Prof. Fernando Aiuti in Rome in early 1983, and Dr. Paganelli was charged, as Meeting secretary, with the task of setting the agenda for a first informal meeting to be held in Roma later the same year and sending invitations directly to scientists active in the field, many of them members of the WHO council on Primary Immunodeficiencies. Among them were Prof. J.C. Griscelli and Prof. J.F. Soothill.



Five meetings were organized on a biennial basis, starting with Viterbo (Italy), Paris, Oxford, Lugano and Sitges (1994) where the transformation of the Group in a Society was decided. A BioMed I Concerted action grant of 338 K Ecus was obtained by the EGID for start by a consortium led by Prof A. Fischer. Then the ESID began a new life.

Some of the photos reflect the work in organizing biennial meetings, circulating a quarterly bulletin, starting an European Registry of Primary Immunodeficiencies, and publishing a series of books I-VI Progress in Immunodeficiencies (see photo).

Establishment of IPOPI announcement

Sponsored by



Biomedicine Editorial Office
St. Alban-Anlage 66
4052, Basel, Switzerland



Editor-in-Chief
Prof. Dr. Felipe Fregni
Harvard Medical School, USA;
Harvard T.H. Chan School of Public Health, USA



Copyright © 2024 Author Roberto.paganelli@unicamillus.org



Figure S5. Poster at the 21st biennial meeting of ESID (Marseille, 2024) on the history of EGID.