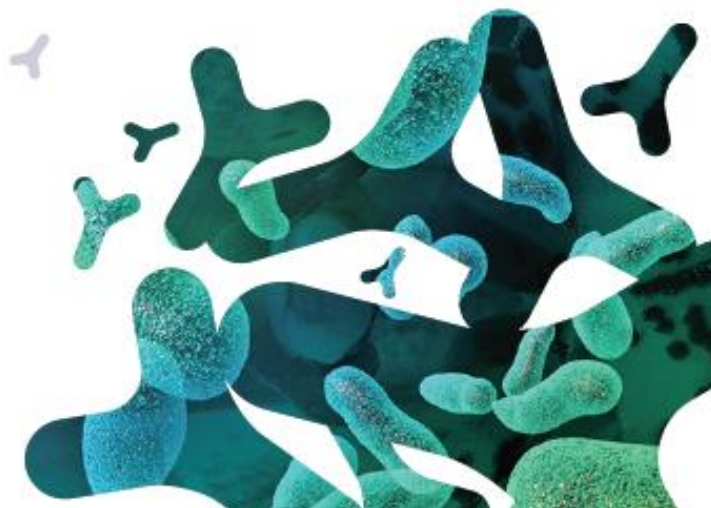




European Society
for Immunodeficiencies



TOGETHER WE CAN CHANGE THE LIVES
OF THOSE
AFFECTED BY PID
www.esid.org

Policy plan (‘BELEIDSPLAN’)

prepared by the ESID Administrative Office

October 2016

Contents

1. About ESID	2
1.1 General Description	2
1.2 Mission	3
1.3 Current Board Members.....	3
2. Activities	4
2.1 Biennial Meeting	4
2.2 Focused Meetings.....	4
2.3 Working Parties	4
2.3.1 Education	4
2.3.2 ESID Juniors	5
2.3.3 Genetics	5
2.3.4 Clinical.....	6
2.3.5 Registry	6
2.3.6 Inborn Errors	6
2.3.7 PID Care in Development	6
3. Global PID Alliance	7
4. Finances.....	7
4.1 How is our income generated?.....	7
4.2 Use of funds.....	7
4.3 Reserves	7
Appendix	8
1.1 ESID Constitution.....	8

1. About ESID

1.1 General Description

The European Society for Immunodeficiencies (ESID) is a non for profit association that was created in 1994. ESID has been striving to improve the knowledge in the field of Primary Immunodeficiency (PID) by encouraging research, developing educational programs and fostering cooperation among all those involved in the diagnosis, treatment and management of these diseases.

ESID is organized in 7 working parties – Inborn Errors, Clinical, Education, Genetics, Registry, ESID Juniors, PID Care in Development. In order to perform its mission ESID organizes several activities such as

- ESID Biennial Congress
- ESID Focused Meetings
- ESID Online Education
- ESID Summer School
- Endorsed activities
- Awards and Grants
- ESID Registry
- ESID Guidelines

The ESID Constitution is attached as Appendix 1.

1.2 Mission

ESID believes that every child, adolescent and adult born with a defective immune system has the right to benefit from both clinical and scientific knowledge.

Therefore, our mission is to enable patients with primary immunodeficiency diseases to live their lives to its full potential by improving awareness, diagnosis, treatment, education and understanding of these diseases.

As the leading society in the field, ESID is committed to promote collaboration between healthcare professionals, patient organizations, industry and governmental bodies and to foster education and research.

The ESID motto and theme is: "Together we can change the lives of those affected by PID"

1.3 Current Board Members

Title	Name	Institution	Country
President	Prof Andrew Cant	Great North Children's Hospital	UK
President Elect	Prof Isabelle Meyts	Pediatric Immunology at the Children's Hospital of the University of Leuven,	Belgium
Secretary	Dr Mirjam van der Burg	Erasmus MC	The Netherlands
Treasurer	Dr Fabio Candotti	Centre hospitalier universitaire vaudois	Switzerland
Education	Dr Eleonora Gambineri	University of Florence, Department of Sciences for Woman and Child's Health	Italy
Registry	Dr Nizar Mahlaoui	CEREDIH: Centre de Référence Déficits Immunitaires Hérités	France
Clinical	Dr Andrew Gennery	University of Newcastle upon Tyne	UK
PIC Care in Development	Dr Peter Jandus	Hôpitaux Universitaires de Genève	Switzerland
Genetics	Dr Kaan Boztug	Research Center for Molecular Medicine of the Austrian Academy of Sciences	Austria
Juniors	Dr Peter Olbrich	Hospitales Universitarios Virgen Macarena y Virgen del Rocio	Spain
2016 Congress President	Dr Oscar de la Calle	Hospital de Sant Pau	Spain
2018 Congress President	João Neves	Hospital Dona Estefania, Pediatric University Hospital	Portugal

2. Activities

In order to meet its goal ESID organizes various activities and events throughout the year.

2.1 Biennial Meeting

ESID organizes biennial congresses. The goal of the ESID Biennial Congress is to bring together leading clinicians and scientists to share recent momentous scientific advances in the field of primary immunodeficiencies and related diseases. This biennial conference also gathers the patient organization (IPOPI) and the nurse organization (INGID), allowing to assemble a global audience and offers a unique opportunity to interact at different interfaces. The aim of ESID is to bring the latest science in this rapidly moving field to the clinicians in a way no other meeting can. ESID's biennial meetings are the world's largest and most important meeting devoted to Primary Immunodeficiencies with over 3000 attendees.

2.2 Focused Meetings

The ESID Board has decided to organize a more focused meeting in the biennial meeting off-years to enable clinicians to keep up to date with the rapidly evolving world of primary immunodeficiencies. These meetings will be more focused on all aspects of a specific defined area and more interactive between clinicians and scientists.

For 2017, the focus of the meeting will be immune dysregulation as manifest in primary immunodeficiencies, auto-inflammation and auto-immunity; pathophysiology, diagnosis and treatment. We actively want to involve colleagues in auto-immunity and auto-inflammation so as to ensure that this is a cutting edge meeting, bringing together the latest research and understanding in these converging fields. To facilitate this, we would like to move away from too many parallel sessions in this meeting, but will also have lively interactive Educational sessions, further developed in line with suggestions from our members.

2.3 Working Parties

2.3.1 Education

The Educational Working Party of ESID is formed by the Chairperson and other Faculty members of the ESID biennial Summer School. Its goal is to offer educational opportunities regarding Primary Immunodeficiencies to young people starting in the field to enthuse, inform and encourage the next generation of leaders in PID practice and research throughout Europe.

ESID Summer School

The educational flagship event of ESID comprises of 5 days of interactive talks and workshops led by leaders in the field intertwined with social interaction in a pleasant setting. The applicants are selected on the basis of their achievements in the field.

Biennial Meeting Educational Day

The ESID Educational Day is organized as part of the biennial ESID meeting. This day is meant for interaction, networking and education for ESID junior members and other junior attendants of the biennial ESID meeting. Plenary and poster sessions, and breakfast or 'sunrise' sessions form part of the varied program.

Travel grants

The Educational Working Party awards travel grants to the Biennial ESID meeting and to the ESID Summer School and other affiliated meetings.

Grants and Fellowships

The Educational Working Party awards fellowships to ESID junior members, consisting of short-term fellowship, medium term fellowship and long-term fellowships.

Other meetings

The Educational Working Party supports other meetings with travel grants for junior participants, such as the ESID Prague Spring meetings, and other - often one-time - meetings and workshops after these have been approved by the ESID Board.

ESID Education Online

Education – empowerment of health professionals, anytime, anywhere.

ESID developed an online educational portal which acts as the repository for vital information about primary immunodeficiencies including case studies, webcasts and other educational material. This educational tool is exclusively accessible for ESID Members.

2.3.2 ESID Juniors

ESID Juniors WP is an interactive forum for young immunologists, clinicians, researchers and any ESID member who would like to participate. The mission of the forum is to promote the development of the next generation of clinicians and researchers with an interest in Primary Immunodeficiencies. The ESID Juniors WP achieves its goals through ESID meetings, networking opportunities, PIDs Summer Schools, educational resources and career advice.

In the map of European Centres ESID provides information on centres available for clinical or laboratory internship or fellowship. All ESID junior researchers and clinicians are invited to make their contribution to the Young Researcher Corner and actively take part in showcasing their latest research and topics.

ESID Talent Award

The intention of this award is to grant Juniors with ESID mid-term fellowships (2014-2015) the opportunity to share their experiences, projects and results with the ESID community. This award is envisaged to acknowledge those candidates with the most remarkable achievements as a direct result of their fellowship projects.

Examples for those achievements are (but not limited):

- Presentations at scientific meetings
- Publications
- Prizes granted by scientific societies
- Establishment of collaborations between different groups or centers
- Clinical/research appointments in reference centers
- On-going clinical or basic research projects with yet unpublished results

2.3.3 Genetics

The ESID Genetic Working Party wants to help to connect and support the collaborative clinical, genetic laboratories and research units associated with the ESID society. In order to facilitate access to information for genetic evaluation on primary immunodeficiencies (PIDs) to the clinicians and ESID members for their patients, the ESID working party has defined specific aims:

- Identify the different laboratories in Europe and abroad which perform genetic and prenatal genetic diagnostic for PIDs.
- Provide this information on the ESID Website to ESID members.
- Develop consensus statements for genetic diagnosis of PIDs.
- Establish links from the ESID website to various immunodeficiency websites and genetic laboratories about the already identified mutations in PID genes.
- Link with the ESID Registry to improve documentation.
- Finally, in the technological “advances” context in genomics with the development of the next-generation sequencing (NGS) for the PIDs’ diagnostic, the ESID Genetics WP has organized a “PID next-generation sequencing consortium” with following goals:
 - Efficiently implement and exchange experiences of genetic laboratories using NGS

- Exchange mutation data, genotypes and phenotypes (for the interpretation of 'new' variants)
- Develop European wide consensus guidelines for PID NGS data handling and patient information/informed consent forms

2.3.4 Clinical

The ESID Clinical Working Party aims to support the collaborative clinical research and education among the centres. In order to achieve this task following specific aims have been defined:

- To create and update the definition of primary immunodeficiency disorders (PIDD)
- To foster clinical surveys and trials for patients with PIDD
- To develop consensus statements for diagnosis and therapy of PIDD
- To support quality and comparability of diagnostic procedures for PIDD
- To support exchange between centres for clinical education

2.3.5 Registry

The ESID Registry is the largest PID database worldwide. The ESID Registry has been recently re-designed to provide a major contribution to the following:

- Epidemiological tool for the PID scientific and medical community to enhance research and for PID advocacy at the European and international level
- Clinical and translational research (updated clinical criteria,)
- Improvement of diagnostic and therapeutic strategies
- Identification of novel disease-associated genes
- Improvement of quality of life of patients and alleviate the burden of disease
- Awareness and education of physicians and healthcare professionals

2.3.6 Inborn Errors

The ESID Inborn Errors Working Party works very closely with the EBMT Inborn Errors Working Party (IEWP). The aim of the working party is to improve the outcome of transplant and gene therapy for severe congenital immunodeficiencies through:

- enhanced interaction between centres involved in the application of BMT to treat severe congenital immunodeficiencies
- undertaking retrospective and prospective collaborative studies to look at the outcome of transplant for these conditions
- education of individuals involved in the care of severe immunodeficiencies
- development of guidelines for treatment of severe congenital immunodeficiencies
- the development and use of a common registry (SCETIDE, www.scetide.org) to document and analyse results of treatment

2.3.7 PID Care in Development

The PID Care in Development Working Party aims at building up an E-learning platform in order to offer a global access to best knowledge and most recent science achievements for clinical application in the care of primary immunodeficiencies.

3. Global PID Alliance

The European Society for Immunodeficiencies (ESID) formed an alliance with four international societies focused on primary immunodeficiency representing the five major continents. Together they have formed the International Alliance for Primary Immunodeficiency Societies (IAPIDS).

The agreement made by the Asia-Pacific Society of Immunodeficiencies (APSID), African Society for Immunodeficiencies (ASID), European Society for Immunodeficiencies (ESID), the Latin American Society for Immunodeficiencies (LASID), as well as The Clinical Immunology Society (CIS) was signed and announced at the ESID Annual Meeting in Barcelona, Spain on September 21, 2016.

“The creation of the Alliance is an extraordinary accomplishment in global collaboration that only serves to further the mission of all of its members with the ultimate goal of promoting excellence in patient care,” said CIS President Jordan Orange, MD, PhD.

The IAPIDS exists to advance the member professional societies in education of those engaged in the care of PID patients and promote member societies in disseminating and advancing the basic, translational and clinical science of PID and related knowledge all in the name of advancing the well-being and care of patients affected by PID and related conditions.

4. Finances

4.1 How is our income generated?

The society derives its funding mainly from the following sources:

- Membership
- Congress profits
- Sponsorship and gifts

4.2 Use of funds

ESID uses the received funds to support the overall mission of the society. The main focus herewith is to invest into educating medical professionals and provide meeting and networking opportunities for such goal.

ESID funds can be used for the following purposes:

1. Funding studies on co-operative European data of immunodeficiency diseases.
2. Funding activities of the Working Parties, e.g. reasonable travel expenses to Working Party meetings taking place outside the Biennial Meeting.
3. Funding the dissemination of information by the Secretary to members of ESID.
4. Funding of other administrative costs considered necessary by the Board.
5. Maintaining the ESID online Registry.
6. Maintaining the ESID website.
7. Organizing the biennial ESID Summer Schools, and biennial ESID Educational Days.
8. Publication of the ESID Newsletter and Supplements.

Our board members are not paid for their services and they are volunteers.

4.3 Reserves

The society would like to maintain a minimum reserve in order to support the running of the society and its activities in case of an unsuccessful biennial meeting or other financial losses by unforeseen global events and/or force majeure.

Appendix

1.1 ESID Constitution

The forerunner of the European Society for Immunodeficiencies, (hereafter referred to as ESID), was established in September 1983 in Rome, Italy, as an informal group (EGID) interested in sharing experience and developing co-operative studies in the field of immunodeficiency diseases. In the 1990's the number of co-operative teams has risen substantially and this expansion has been commensurate with a growth in the complexity of the organisation, necessitating a clearer definition of its purpose and activities. At the Biennial Meeting in Sitges in 1994 the first constitution of ESID was approved. In 2000 the constitution was revised in Geneva in order to better reflect the evolution of this organisation. In 2008 the Constitution was adapted when official Articles were made up by drawing up a Dutch notarial deed.

§1

THE EXECUTIVE BOARD

The Board consists of the President, the Secretary, the Treasurer, the chairpersons of all Working Parties. Each term of office is 2 years for the President, Secretary and chairpersons of all Working Parties, renewable at the next Biennial meeting, but limited to 2 terms (4 years) only. The Treasurer can serve 4 terms (8 years). The President-Elect is elected at the General Assembly two years prior to office, the President of a Biennial Meeting is elected at the General Assembly during the Biennial Meeting four years before the Biennial Meeting he/she will organise. The Past-President is part of the Board for two years after his/her presidency, the President-Elect for two years before his/her presidency, the president of the Biennial Meeting from the two years before to the two years after the Biennial meeting that he/she is organising.

Decisions are taken by a majority vote. The President has the deciding vote, if the vote is otherwise tied. The Board should meet at least once a year.

ESID Board members must be full members of ESID. They may be citizens from any country, but need to work in Europe for the time of his/her service.

All ESID Board members shall declare any financial or other possible conflict of interest to the ESID board in writing.

The members of the board shall not receive any payment for exercising their office. The board shall however reimburse the costs reasonably incurred by the board members in the exercise of their office and the board shall establish an annual budget for this purpose

(ratified during General Assembly 2014-11-01, Prague)

§2

THE GENERAL ASSEMBLY

The General Assembly is open to all members of ESID and to the President and the Board of the International Patient Organization for Primary Immunodeficiencies (IPOPPI) and the International Nursing Group for Immunodeficiencies (INGID). It normally takes place at the time of the Biennial ESID Meeting. It is chaired by the President and includes the Presidential report, the Secretary's report, the Treasurer's report and any other business. The agenda for the meeting is made available over the internet, mailed, and/or published in the ESID Newsletter at least one month in advance.

All ESID officers will be elected by electronic voting on the protected part of the ESID website. Votes may only be casted by electronic voting. The poll will open one month prior to the General Assembly and will close at the day preceeding the day of the General Assembly at 12:00 noon (Central European Time). To facilitate this, at least three months prior to the poll, the Board will encourage ESID members to consider their candidature for available posts. This is primarily the responsibility of the Secretary. At least one month

prior to the meeting, available candidates will present themselves to the ESID members in the ESID Newsletter and/or on the ESID website.

Either during the General Assembly or by electronic voting the ESID full members also have the following obligations: To elect the president and the location of the Biennial Meeting; To decide on the biennial fee for membership of ESID as proposed by the Board; To either agree or disagree with policy decisions as proposed by the Board; To make proposals as to starting/discontinuing activities of the Society; To decide about amendments to the Articles, the Constitution and dissolution of the Society (see also §13).

§3

ESID MEMBERS

ESID members may be citizens of any country, working anywhere in the world, however, they shall be MDs, PhDs (biology), Veterinarians, Pharmacists, Dentists, or graduate students in any of these fields, or PhDs of other fields and corresponding graduate students. ESID full and associate members can participate in co-operative ESID and ESID related EU/Biomedicine studies; they can enter reports on immunodeficiency diseases and patients into the ESID registries; they are entitled to a password to enable them to enter the restricted part of the ESID website. All members are entitled to receive ESID Newsletters and regular information about meetings, co-operative studies and results of ESID research projects, ESID summer schools etc.;

The ESID Board has the right to expel an ESID member (e.g. due to malpractice in science) by a two-thirds majority vote.

§4

WORKING PARTIES

The Board takes the initiative to establish and close Working Parties. Each Working Party is headed by a chairperson who becomes a member of the Board. Seven Working Parties (Clinical, Genetics, Registries, SC Transplantation&Gene Therapy, Juniors, Education and PID care in development) are presently operating within ESID, but more can be established if and when required. The Chairperson of each Working Party is elected by electronic voting by all ESID full members every two years and may stand for one re-election. The Chairpersons of the Working Parties must be full members of ESID. They may be citizens from any country, but need to work in Europe for time of his/her service. The substructure of the Working Party is determined by the Chairperson. The Working Party Chairpersons give an annual report to the Board on Working Party activities and publications and a biennial report to the General Assembly. The Chairpersons of the Working Parties shall declare any financial or other possible conflict of interest to the ESID board in writing.

§5

DEFINITION OF EUROPE

For the ESID Europe shall be defined as: all countries of the European Union plus Iceland, Norway, Switzerland, Serbia, Bosnia, Montenegro, Croatia, Albania, Macedonia, Andorra, Monaco, Lichtenstein, Ukraine, Belarus, Russia, Moldavia, Turkey, and Israel.

§6

THE PRESIDENT

The President shall be a full member of ESID of at least two years standing. He/she may be a citizen from any country, but needs to work in Europe for time of his/her service. He/she is elected by electronic voting by all ESID full members, and serves for two years. The President may stand for one re-election. He/she may

thus serve for a maximum period of 4 years. The President serves as President-Elect for two years before becoming President. The President promotes the activities of ESID. These include fund raising, co-ordination of Working Party activities, giving guidelines to the organisers of the Biennial Meeting, and in negotiations with other organisations.

§7

THE SECRETARY

The secretary is elected for two years. He/she must be a full member of ESID. He/she may be a citizen from any country, but needs to work in Europe for time of his/her service. He/she may stand for one re-election. The secretary writes the annual business plan with the executive officers, organises board meetings, agendas, keeps and circulates the minutes, chases up the reports for the General Assembly meetings, writes the agenda and minutes and circulates these to the members through the ESID Newsletter and ESID website.

§8

THE TREASURER

The Treasurer is elected for a period of two years which is renewable three times. He/she must be a full member of ESID. He/she may be a citizen from any country, but needs to work in Europe for time of his/her service. He/she may thus serve for a maximum period of 8 years. He/she collects the two-yearly membership fee and accounts for the use of the funds for ESID purposes. He/she is also responsible for fundraising and maintaining the finances to support the infrastructure of ESID.

§9

INFORMAL NETWORKS

ESID encourages the formation of informal national networks among its members to locally promote the aims of ESID. The chairman/ co-ordinator of such a network (presumably elected for a limited time period) would have an advisory function to the Board. They will promote the interaction between ESID and National Immunology and Clinical Immunology Societies or Groups.

§10

MEMBERSHIP FEE

Each member pays a two-yearly membership fee to ESID which is fixed by electronic voting of all ESID full members during the month preceeding the General Assembly after proposal by the Board. The fee can be reduced by the Board in particular circumstances on request. In addition, the Board has the discretionary power to identify exceptional circumstances and modify the fee for some countries. Members under 35years of age pay a reduced membership fee (50% of the full fee).

§11

BIENNIAL MEETING

Meetings of ESID take place once every two years. The President and the location of the Biennial Meeting is decided by electronic voting of all ESID full members during the month preceeding the General Assembly upon proposal by the Board or members. The local host must be a full member of ESID. The ESID meeting is organized by a local steering committee in close collaboration with a congress organizing company. The scientific content of the meeting is proposed by a scientific committee. This scientific committee is suggested

by the congress president but approved by the ESID board. The ESID board needs to approve the scientific content of the meeting. In case of a dispute, the ESID board will have the final say.

§12

USE OF ESID FUNDS

ESID funds consist of subscription fees and of funds raised from public organisations, charities and pharmaceutical companies.

ESID funds can be used for the following purposes:

1. Funding studies on co-operative European data of immunodeficiency diseases.
2. Funding activities of the Working Parties, e.g. reasonable travel expenses to Working Party meetings taking place outside the Biennial Meeting.
3. Funding the dissemination of information by the Secretary to members of the Group.
4. Funding of other administrative costs considered necessary by the Board.
5. Maintaining the ESID online Registry.
6. Maintaining the ESID website.
7. Organising the biennial ESID Summer Schools, and biennial ESID Educational Days.
8. Publication of the ESID Newsletter and Supplements.

§13

CHANGING THE CONSTITUTION

Amendments to and changes of the Constitution are made by electronic voting by all ESID full members with a two-thirds majority vote. Notice of the intention to change the Constitution shall be made available to all members at least 4 weeks before the relevant business meeting of the General Assembly.

(ratified during General Assembly 2008-10-17, 's-Hertogenbosch)

§14

LIQUIDATION OF THE SOCIETY

Following dissolution, the board members shall liquidate the association. The board can decide to appoint other persons as liquidators. In the resolution to dissolve the association, the destination of the liquidation balance will be spent (as much as possible in accordance with the goal of the association) to an institution of public utility (i.e. an ANBI) or in another way with which the public interest is served.

(ratified during General Assembly 2014-11-01, Prague)