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ESID Biennial Meeting - Prague, Czech Republic

29 October -1 November 2014

The ESID 2014 Meeting's preparation has started a while ago!

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Participate in the Stem PAD study

A study on the outcome of transplant for antibody deficiency and CVID in collaboration with EBMT Inborn Errors WP and ESID BMT and Clinical WP.

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ESID Prague Spring meeting 2013

13-14 May 2013

Prague

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In Memoriam

Known by all of us for her knowledge in the field of immunodeficiencies and for her willingness to improve the health of immune-deficient patients, Claire-Michèle Farber passed away.

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NEWS @

President's Corner

Dear friends

Well, it is now half a year after the wonderful meeting in Florence (2000 attendees!), and we already started to work on the Prague meeting in 2014. Anna Sadiva, who serves as the president of the meeting, is already working "in full gear" to construct an interesting meeting and exciting social events.

Several new board members joined us and in the last board meeting new ideas regarding ESID have come up. We are going to build a new website, which we hope will be friendlier to the user and ESID registry (the biggest of its kind) will continue to collect more data, which will enable members to learn and report on various PID disorders.

ESID is trying to push forward the implementation of neonatal universal screening for severe combined immunodeficiency (SCID) which was found to be very useful in several states in the US. Another decision taken by the board is that each working party will have 5000EU for studies or any other activities concerning each working party. So, I encourage you to submit proposals directly to the chairperson of the working parts.

I would like to take this opportunity to welcome again the new members of the board with whom I am sure, ESID will continue to lead in the field of Primary Immunodeficiency.

Wishing you all a lovely summer

Amos Etzioni - President

Secretary's Corner

Dear ESID members,

the first ESID board meeting of 2013 has been hold in Amsterdam last January. As discussed during the General Assembly, the Society Website needs to be improved or redesigned. To this end, the ESID board has delegated Marta Rizzi to contact website providers. Unfortunately the original option to update and improve the current website is of difficult feasibility. The provider Piccobello, who designed ten years ago the current ESID website cannot update it for technical reasons. The platform has become obsolete and the cost of this operation would be more expensive than a new one.

Thus, the ESID board has now nominated a committee (Marta Rizzi, Andy Gennery and Esther de Vires) to evaluate new offers. Since we are finalizing the offers, it would be great to receive your criticisms and suggestions. Please contact me or Marta Rizzi (ESID Junior) to send your comments and requests.

ESID FINANCIAL SUPPORT: ESID has decided to support the next LASID symposium. B. Gaspar and A. Fischer will represent ESID at this meeting. Moreover, at ASID, four young delegates will receive travel awards supported by our Society.

ESID WORKING PARTY: We have approved the decision to provide to each WP an amount of 5000 Euros to be used for activities. An application form for project proposal will be posted soon on our website.

ESID GRANTS AND AWARDS:

Please those who are interested in fellowships, visit our website. The deadline is June 15, 2013.
Here are the open fellowships:

Short-term fellowship - EUR 1'000

DESCRIPTION: 4 scholarships of 1,000 Euros are available for current ESID Junior members (you must be under 35 but age will not be an absolute limit), who are physicians or scientists in training, interested in learning diagnostic/therapeutic procedures or lab techniques in the field of Primary Immunodeficiencies.

Medium-term fellowship - EUR 3'000

DESCRIPTION: One fellowship will be awarded to a current ESID junior member (you must be under 35 but age will not be an absolute limit), who is a physician or a scientist under specialist training, interested in pursuing a research project in the field of primary immunodeficiencies.

Long-term fellowship - EUR 10'000

DESCRIPTION:
One fellowship will be awarded to a ESID junior member (you must be under 35 but age will not be an absolute limit), who is a physician or a scientist under specialist training, interested in pursuing a research project in the field of primary immunodeficiencies.

Finally, we are working to improve the bidding guidelines process. A letter of intent describing the city and venue should be sent to the ESID secretary by April 30, 2014. Kenes will assist us to revise the bids and evaluate the Site Selection Reports.

Please let me know if you have any comments or suggestions.

Anna
villa.anna@hsr.it
Tel +390226435273

News: ESID Working Parties

BMT & Gene Therapy

Dear Friends and Colleagues,

We write to formally request your active participation and collaboration on the project titled: “A natural history study of long term clinical outcomes of patients with X-linked hyper-IgM syndrome (XHIGM)”.

Funding for this project is provided by a grant through the Jeffery Modell Foundation. The study is approved by the Institutional Review Board (IRB) at the University of Texas Southwestern Medical Center in Dallas, Texas, USA where the data analysis will take place. We hope the results of this analysis provide a foundation that will allows future prospective treatment studies for patients with XHIGM.

The study uses a Redcap survey format that should be easy to complete (please see link below)

https://ais.swmed.edu/redcap/surveys/?s=MkRuhT

As many of you know, the molecular diagnosis of XHIGM is becoming readily available for clinicians. An important clinical question yet to be answered is what form of therapy provides the best long term

outcomes for such patients: Transplant vs. no transplant with medical management.

This is an open invitation and request to participate; all participants will be invited as authors on the final manuscript.

We look forward to working with you in this effort to better the lives of our patients.

Warm regards,

Andrew Cant, Andrew Gennery, & Maite de la Morena, MD
Associate Professor of Pediatrics and Internal Medicine
Division of Allergy and Immunology
University of Texas Southwestern Medical Center in Dallas
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Phone 214 456-5161
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Email: maite.delamorena@utsouthwestern.edu

Clinical

Dear friends and colleagues,

The Clinical Working party will participate in the efforts of the ESID registry to elaborate diagnosis working definitions for PID patients for whom a confirmed genetic diagnosis is not yet available.

Fortunately, diagnostic and therapeutic care for patients has considerably improved over the years; this means that more and more paediatric patients with PID are surviving into adulthood. For these PID patients who have been diagnosed in infancy and who have not been transplanted, many questions remain and a common effort of paediatric and adult immunologists is needed to guarantee a smooth and efficient transition. These patients also often present disease specific problems or autoimmune/dysimmune related complications, for which treatment options are not well established. A multi-centre survey may be very helpful to address important issues that cannot be resolved on the local level… Close interaction with the ESID registry will be essential.

In order to better coordinate and focus research within the Clinical Working party, a steering committee is indispensable and needs to be established. Some of you have already shown their interest in participating, others might be interested and are more than welcome to join our efforts… So do not hesitate to contact me by mail, if you wish to contribute (despina.moshous@inserm.fr).

Best wishes

Despina Moshous

Education

Dear all,

We have received 40 applications for the ESID Summer School in Hersonissos, Crete, and are in the process of selecting the participants. They come form 29 countries in 6 continents! We look forward to this

meeting in Greece from September 25 tot 29!

Best regards,
Esther de Vries
Chair Educational Working Party

Genetics

ESID Genetic Working Party Announcement

The ESID Genetic Working Party (WP) wants to help with connecting and supporting the collaborative clinical, genetic laboratories and research units associated with the ESID organization. The exchange of genetic diagnostic tools will improve the diagnosis and the genetic counseling of patients with primary immunodeficiencies (PIDs), which are important for the patients' supporting care.

In the technological advances' context in genomics, we organized the first workshop about next-generation sequencing (NGS) in PIDs. This meeting took place at the Amsterdam airport, on March 15th 2013 "PID next-generation sequencing consortium-ESID March 15th 2013 Schiphol." Fifteen participants attended; they came from Austria, Belgium, France, Germany, Italy, the Netherlands, Norway and UK.

This workshop's goals were:

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

In the next issue of the ESID Newsletters, the conclusions of this first workshop will be reported.

Our best,
Capucine PICARD for the Genetics WP of ESID

Registry

Redesign of database

The ESID Registry steering committee members met on December 5, 2012 in order to take the development of the new datasets forward. Taco Kuijpers and Isabella Quinti as experts on specific disease categories also participated in this meeting, as well as Prof. Vach, a biostatistician from University Freiburg with a special interest in registries who has been an advisor to the project since 2011.

Several important decisions were made in this meeting and were put into action thereafter. The level 1 dataset which represents the core of the new system and covers items to be used in epidemiologic analyses has been finalised. Besides data on the PID diagnosis, it will cover HSCT, gene therapy and immunoglobulin replacement. One key difference to the old system will be the mandatory yearly follow-up registration. The database team in Freiburg is now working on the implementation of a new web-based system which is projected to go online this summer. It will consist of forms covering the level 1 dataset. The so-called level 2 datasets which provide more detailed data on clinical manifestations, laboratory values and therapy will be designed for each of the 8 IUIS categories and implemented at the next stage. The steering committee has realized that these datasets require more work and discussions than initially anticipated.

The transfer of existing data from the current registry represents a key issue. The level 1 datasets mostly consists of data items available in the current system, which makes data transfer possible. A process for monitoring data quality before transfer to the new system will be implemented and funds will be made available to the national registries to implement this quality control in the best possible way (see below). Another key issue is the stringent definition of diagnostic criteria in those cases where a genetic diagnosis has not been established (e.g. CVID). Here, we will have to use “working definitions” because the efforts to standardize definitions are not likely to be completed in the near future. Once level 2 is in place, there will be a second transfer of data (including lab values).

Although not all data will be transferred to the new system, we would like to emphasize that all data that has been entered so far will remain available to the documenting centres and can be accessed by them anytime.

Models for data entry
The steering committee also discussed the differing circumstances at the documenting centres. Some centres have their own funding and trained study nurses or data entry personnel, while others rely on a single physician’s commitment to the project. The data entry modalities have an important impact on data quality. We have therefore decided to explore the different models for data entry in more detail (a survey has been initiated) and develop SOPs on the basis of this service that account for both data quality and practicability.

True costs
Another purpose of this survey is to estimate the true costs of the registry. We believe that it is important to document (to the ESID Society, also to our sponsors PPTA) the resources which documenting centres and national registries commit to the project and where these resources come from.

Support for national registries
The steering committee has decided that a total of EUR 20,000 from the annual Registry budget will be used for initiatives by national registries, such as scholarships for PhD students. For the current year, priority will be given to those projects that implement a data quality management plan before transfer of the data to the new system. A call for projects will be discussed at the next steering committee meeting and issued thereafter.

Information on the Registry Steering Committee
For more information on the tasks and the current members of the Registry steering committee, please visit the registry section on the ESID website, or **Click here**
The page also provides information on upcoming steering committee meetings. The next meeting will take place in Paris on April 26, 2013.
All ESID Members are invited to contribute issues to the agenda.

Cancer in PID
In late 2012, the USIDnet consortium suggested a common analysis of data from the ESID and USIDnet registries with respect to the incidence of cancer in PID. The steering committee has reviewed this suggestion and supports it. However, due to large differences in reported cancer incidence in the initial screening of the data of the two registries, a common European/US analysis does not appear useful at this time because of different settings that influence data quality and reliability of results. However, the efforts shall be closely communicated and coordinated between the two initiatives.

Currently, the ESID registry contains retrospective data on more than 560 PID patients with cancer. We sent out an invitation for this study to all documenting centres in November 2012, and very many centres

have sent positive replies since. Ewa Bernatowska, Nizar Mahlaoui and Isabella Quinti have been appointed principal investigators for this study and are now working together on the details for the analysis. We will inform all interested centres on the progress of this project soon.

Benjamin Gathmann, ESID Registry Coordinator
Stephan Ehl, Chairman of the ESID Registry Working Party

ESID Juniors

Dear ESID Juniors,

Spring is coming with her colors enthusiasm and energy, with lots of opportunity for us to deepen our knowledge in immunodeficiency, networking and exchange. During the past months I have been working at a proposal to improve and/or change our current ESID website. I want to thank all ESID Juniors that gave suggestions and opinions on this matter. Thanks to your active involvement through the discussion in the ESID Junior Facebook group **(https://www.facebook.com/groups/esid.juniors/)** we had a voice for the re-styling of our society website. This is an essential instrument for the life of our society, as it conveys information on meetings, congresses, call for action on possible common projects among members, and more. We want to have a easier to navigate website, where we can quickly find what we are looking for, that will increase the involvement of our ESID members in the society. We are looking now at the proposals from different providers and we'll proceed to the next step in the next weeks.

As we discussed during the ESID Junior workshop at the ESID biannual meeting in Florence I wanted to connect 'younger' and 'older' Juniors with a new iniative called 'Peer Mentoring'. The idea is to give the opportunity to Juniors approaching the field of immunodeficiency to get advice on practical matters from 'more' advanced Juniors. This has already informally started in our networking events at the biannual congress, and through our Facebook group. To better organize it, I would like to ask your help and opinion. I will open a question in our Facebook group, so we can find together the best way to do it.
Looking forward a very exciting time is awaiting us. At the end of the summer, from the 25th to the 29th of September there will be the ESID Summer School in Hernissoss, Crete. Looking forward to meet the excellent Juniors that will be selected to participate. In these 5 days 30 Juniors will be exposed to the latest knowledge in primary immune deficiency, with the great opportunity to be in close contact, get advice and network with some of the best scientist in the field. We'll share our experience in the ESID Juniors Facebook group!

In spring there is more than one event coming up, you can see them listed in the top news of our ESID website. I would like to mention the coming Prague Spring meeting (13-14 of May, application still open) organized by Anna Sediva. This meeting has become a fix appointment for Juniors of Eastern and Western Europe to meet and exchange projects, data, ideas and clinical experience, under the mentoring of excellent invited faculty. I would like to thank Anna for her invaluable effort in supporting the Juniors. Anna you are great! The second event I would like to mention the '2nd workshop on Diagnostics of Immunodeficiencies' organized by Klaus Warnatz in Freiburg. It is addressed to the ones of us working in diagnostic labs to share experiences, learn guidelines procedures and pitfalls. Take a look to the call the application is still open! I want to thank all the ESID members organizing meetings, workshops and events, proving opportunity to improve our knowledge on immunodeficiency, exchange ideas, and networking. We really appreciate your effort!
Finally don't miss the opportunity offered by the ESID short (up to 1 month), medium (3 to 6 months) and long (up to 1 year) fellowship. The application is open and the dead line is the 15th of June. Look in our map of Center for fellowship, talk to you peers, ask your advisor and gather ideas to go and make a

working experience in another center. It is the best you can do to your career!

I conclude thanking the effort of all active Juniors helping and participating to many of our activities and in particular the team responsible of the Young researcher corner Sara Ciullini, Imma Brigida recently joined by Stefania Giannelli. Thanks a lot! All of you make the ESID Juniors lively, useful, and a great fun!

Have a fresh, warm and sunny spring, get involved and share your experience!

Marta

Young Researcher's Corner

EPSTEIN BARR VIRUS – the ability to persist in the human immune-system and to immortalize B cells in culture

Stefania Giannelli (HSR-TIGET Milano, Italy)

The Epstein-Barr –Virus (EBV), also called human herpesvirus-4 (HHV-4), is a double strand DNA virus belonging to the herpes family, and is one of the most common viruses in humans.

EBV takes his name from the Professor Michael Anthony Epstein and Yvonne Barr, who discovered and documented the virus. Virus particles were identified in cultured infected cells, and the results were published in the Lancet journal in 1964 by Epstein MA, Anchor B and Barr Y. In the following years serological markers were identified in cell lines and in 1968 mimicking some forms of EBV–related infections, was discovered that EBV can directly immortalize B cells after infection. The human EBV preferentially infects B cells, but occasionally infects other cell types, especially epithelial cells. EBV is usually rapidly cleared by healthy human immune system.

Human herpes viruses have a unique capacity to establish a life-long latent infection in the host, whereby the virus can persist within specific host cells, and protects itself from immune recognition by limiting viral gene expression. The establishment of EBV latency is the final phase of the four different EBV infection stages: the growth phase in which the virus activates resting B cells to became proliferating lymphoblasts, the default phases in which EBV provides survival signals to infected lymphoblasts to induce their differentiation into memory B cells and the maintenance of persistently infected memory cells and finally the latency phase that allows persistence of the virus in resting recirculating memory cells in a way that is non-pathogenic and not detectable by the immune system.

The human immune response is generally very successful at controlling infections and minimizing symptoms during primary and persistent infections; however, herpes viruses are responsible for several diseases including conditions associated with primary infections. These clinical problems are more common and severe in immune-compromised individuals such as transplant patients on immunosuppressive medication and human immunodeficiency virus (HIV)-infected individuals, because of an impaired adaptive immune system. In particular, the most benign transient infection that affects adolescent or adult is the infectious mononucleosis, in which 50% of T cells and 25% of the memory B cells are specific for the virus during peaks of infection. From this infection EBV will latently persist in the individual's B cells life-long and can wake up in the moments of immune weakness.

However, there is a dark side for this seemingly inoffensive virus. A simple mutation in small and signaling molecule, the SLAM-associated protein (SH2D1A/SAP) diverts EBV infection from a benign persistence to an acutely aggressive disease, X-linked lymphoproliferative disease (XLP), which rapidly kills the infected individual. The EBV latency phase in combination to environmental and genetic cofactors could links EBV

with neoplastic malignancy.

EBV is present in malignant pathologies such as the Burkitt's lymphoma (the tumor in which the virus was discovered, but without a clear role in the pathogenesis of the tumor), the nasopharyngeal carcinoma, the Hodgkin's disease and the immunoblastic lymphoma. It is also present in heterogeneous group of B-cell tumors that arise in immunocompromised individuals unable to mount an effective cytotoxic T lymphocyte response to these infected cells.

After primary infection, EBV can be detected in the peripheral blood of healthy seropositive individuals. Spontaneous outgrowth of virus carrying B cells from peripheral blood gives rise to B lymphoblastoid cell line in culture and PCR analysis of peripheral blood cell DNA can detect viral genomes.

Also in our lab we can generate immortalized B cell lines. The technical procedure used to establish EBV transformed B cell lines have not substantially changed over the last 25 years. Free EBV particles are produced by maintaining an EBV infected marmoset cell line (e.g. B95.8), which is overgrown and subsequently lysed. Human lymphocyte cultures are inoculated with free virus that enters into B-lymphocytes via their CD2I (CR2) cell surface molecules. As the virus becomes integrated into the B cell, cytotoxic T lymphocytes can be generated, which subsequently kill the infected B cells, leading to transformation failure. A range of techniques has been developed to avoid this. These include removal of T lymphocytes following resetting with sheep red blood cells or immune suppression of T cells using cyclosporin A. An alternative strategy is the incubation of lymphocyte cultures with T cell mitogens such as phytohaemagglutinin (PHA), which induces T cells to rapidly transform into blast cells and die before cytotoxic T cells can be generated.

Current techniques are based on variations of these procedures and use isolated B lymphocytes from blood samples. These are either transformed as fresh cells or following cryo-preservation and storage in liquid nitrogen. Fifteen days after infections in transformed B cell lines viral genomes are detected by PCR or in alternative by FACS is possible to check for CD20, 30, 38 and 27 B cell marker.

We can take advantage from EBV transformed B cell lines considering that the somatic mutation rate of DNA is low (0.3%) so EBV cell lines is largely representative of a wide range of metabolic pathways specific for the individual/patient from whom the cell line was generated. The generation of EBV cell lines is thus especially suitable to study pathologies in which B cells pathways are impaired or to expand the poor B cells pool from immunodeficiency's patients or from tissues not easily available like cerebrospinal fluid of multiple sclerosis or the synovial fluid of rheumatoid arthritis patients. B cell immortalization can be also a valuable tool for the production and characterization of auto-reactive antibodies from patients with autoimmune disease. Furthermore, EBV cell lines could be used for the isolation of therapeutic antibodies for passive vaccination, but also to analyze the antibody repertoire in immune or vaccinated individuals to identify neutralizing, enhancing, or irrelevant epitopes, thus guiding the formulation of candidate vaccines. This "analytic vaccinology" will be particularly useful in the case of highly variable viruses, such as hepatitis C virus or HIV, or highly complex pathogens.

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PID Care in Development

As each year we use an occasion of Rare Disease Day as a momentum to foster our activities of ESID PID Care in Development WP. Rare disease day is an international activity to raise awareness for the need for rare disease research and improved access to treatment for affected individuals and their families. We share the same goals in ESID PIDCD WP. J project is a major tool for raising awareness on PIDs. In February, under the leadership of Laszlo Marodi, a plan for ongoing activities for J project meetings in Central and Eastern Europe was finalized. The J project is amazingly active and is currently in a stage of transition to more official association of working groups from individual countries. Its steering committee has a scheduled meeting in Budapest in May 2013. Thirty six members from 22 countries from Eastern Europe and beyond are going to participate. J project´s main activity, to increase awareness and to help with a diagnosis and treatment of primary immunodeficiency diseases in less developed countries, is ongoing. Further effort is, however, directed beyond awareness campaign and is expressed in a targeted effort to improve a scientific contribution to the field from Eastern part of Europe. To achieve this J project members work on common publications, with first attempts in progress and hope for more in coming years.

The second important activity of PIDCD WP, "Europe Immunoglobulin Map", is available in its 2012 edition. Current version is still lacking large Eastern Europe countries (Belarus, Ukraine, to be completed during J project steering committee meeting in May), however, it nicely shows West to East trend in slow, but ongoing improvement with an access to this basic treatment of PIDs. Trend to switch to subcutaneous treatment is obvious, too, in all parts of a continent.

We hope to do more in upcoming months, together with other ESID WPs. We´ll particularly concentrate of upcoming ESID 2014. Its location in Prague is very important for Eastern Europe and we hope to show not only improved awareness, but also a scientific progress in these countries.

For ESID PIDCD WP, Anna Sediva

ESID Grants & Awards 2013

Find all the information you need about the 2013 ESID Awards & Grants exclusively for ESID members!

Short-term fellowship - EUR 1'000

DESCRIPTION:
4 scholarships of 1,000 Euros are available for current ESID Junior members (you must be under 35 but age will

not be an absolute limit), who are physicians or scientists in training, interested in learning diagnostic/therapeutic procedures or lab techniques in the field of Primary Immunodeficiencies.

DURATION:
Each short-term programme should last up to 1 month.

APPLICATIONS:
The application should include:

(a) Personal letter with a statement of career goals and plans on how to achieve those
(b) A short project plan
(c) CV with list of publications
(d) A letter of invitation from the accepting institution
(e) And a letter of support from the applicants head of department or supervisor

DEADLINES:
1st deadline: 15 June 2013 (2 grants will be awarded)

Please send your questions or application to ESID Administrative Office by email at esid.admin@kenes.com

Medium-term fellowship - EUR 3'000

DESCRIPTION:
One fellowship will be awarded to a current ESID junior member (you must be under 35 but age will not be an absolute limit), who is a physician or a scientist under specialist training, interested in pursuing a research project in the field of primary immunodeficiencies.

FUNDING:
ESID is awarding Eur 3'000.00, to be used for laboratory or clinical research work.
50% of the amount will be received in the beginning of the fellowship and the remainder towards the end.
Awardees are expected to submit a complete report to ESID within a maximum of 3 months after the end of the programme.

DURATION:
Each fellowship should last at least 3 months up to 6 months.

APPLICATIONS:
Each application should include:

(f) Personal letter with a statement of career goals and plans on how to achieve those
(g) A project plan
(h) Curriculum vitae
(i) List of publications
(j) A letter of invitation from the accepting institution
(k) And a letter of support from the applicants head of department or tutor

DEADLINES:
Deadline for applications is June 15, 2013

Please send your questions or applications to ESID Administrative Office by email at esid.admin@kenes.com

Long-term fellowship - EUR 10'000

DESCRIPTION:
One fellowship will be awarded to a ESID junior member (you must be under 35 but age will not be an absolute limit), who is a physician or a scientist under specialist training, interested in pursuing a research project in the field of primary immunodeficiencies.

FUNDING:
ESID is awarding Eur 10.000, to be used for laboratory or clinical research work.
50% of the amount will be received in the beginning of the fellowship and the remainder towards the end.
Awardees are expected to submit a complete report to ESID within a maximum of 3 months after the end of the programme.

DURATION:
Each fellowship should last at least 6 months up to 1 year.

APPLICATIONS:
Each application should include:

(a) Personal letter with a statement of career goals and plans on how to achieve those
(b) A project plan
(c) Curriculum vitae
(d) List of publications
(e) A letter of invitation from the accepting institution
(f) And a letter of support from the applicants head of department or tutor

DEADLINE:
Deadline for applications is June 15, 2013

Please send your questions or applications to ESID Administrative Office by email at esid.admin@kenes.com

ESID 2014 Biennial

The preparation for ESID 2014 actually started even before our last meeting in Florence. The work is now ongoing. You can already check our website, kenes.com/esid2014, and sign for regular updates.

The venue and dates are already fixed. Prague has become a very popular site for organization of international events. Available dates, 29.10.-1.11.2014, are therefore later in October than our previous meetings took place. Prague is, however, still very pleasant in this period of a year and we hope that you all are going to enjoy your stay.

A work on the most important part, the scientific program, was also initiated. Due to a fast progress in the field we expect a very exciting scientific program throughout the meeting. We welcome any suggestion and comments. Please, let us know what would you like to hear and to do in Prague, it is time to shape our meeting according to our needs and wishes.

Please, save the date, and plan your participation in Prague in 2014.

NEWS @

12th ESID Prague Spring Meeting - Report

Report on the 12th ESID Prague Spring Meeting, May 13-14, 2013

Department of Immunology, 2nd Medical School, Charles University, Motol University Hospital, Prague, Czech Republic

The twelfth ESID Prague Spring Meeting was organized by Department of Immunology and Clinic of Pediatric Hematooncology of the 2nd Medical Faculty of Charles University and Motol University Hospital, Prague, Czech Republic, on May 13 and 14, 2013. The meeting took place in its traditional settings in Olympus facility in Prague. It was attended by 32 participants from 9 countries, majority of them from Czech Republic, further from Austria, Egypt, France, Italy, Poland, Ukraine, United Kingdom and The Netherlands, in alphabetical order. The meeting puts an importance on the active participation of young immunologists and gave them the opportunity to present their work in oral presentations.

Since its launch in 2002 the Prague ESID meeting has been devoted to the exchange of information on primary immunodeficiencies (PIDs) between Western and Central and Eastern Europe. The continuous effort to promote exchange of information and rise of scientific levels in Eastern Europe is partly successful. So far several excellent groups were formed in Eastern European countries. There is, however, still visible gap between East and West part of a continent in a diagnosis and care for primary immunodeficiency patients and also in related research activities.

The program of the meeting was divided into four major blocks supported by contributions and supervision of invited speakers. B cell panel was introduced by Menno van Zelm and further was extensively covered by series of lectures on pathogenesis, diagnosis and treatment of B mediated disorders. Rare immunodeficiencies and well defined syndromes included very interesting talks on novel discoveries in disorders of organelle formation, given by Raffaele Badolato, and showed several other novel genetic causes of immunodeficiencies. Anne Puel gave an excellent review on new findings in pathogenesis of mucocutaneous candidiasis. Last afternoon was devoted to novel technologies and laboratory diagnostics. Sufficient amount of time for discussions and a very active and relaxing atmosphere made traditionally creative environment, typical for ESID Prague Spring Meeting series.

Social program was also very interesting. Special evening took place in a newly opened University Club, which belongs to Charles University. Situated in a center of a city and located in a gothic basement, the club provides unusual and inspiring settings for a cultural program. That composed from an opening exhibition of paintings of Academy of Fine arts on the theme Prague, followed by a block of folk songs and yoyo performance. Traditional Czech dinner in a closed by restaurant finished the evening.

The meeting was also organized as a part of the activities related to the Day of Immunology, declared by EFIS on 29th April, 2013 and to Primary Immunodeficiency Week 2013. The meeting is also an event of J projects meetings, promoting awareness about PIDs in Eastern European Countries. ESID Prague Spring Meeting was supported by the Charles University, 2nd Medical School, Prague and by Motol University Hospital, Prague. General partners of this year events were Baxter, CSL Behring, Olympus and Shire, further contributions came from Grifols, Exbio, Octapharma, Schoeller and Synlab. Special support was provided by Czech Immunology Society. The meeting is traditionally supported by Jeffrey Modell Centers Network.

We thank all sponsors and all participants for their contributions and we are looking forward to the biennial ESID meeting in Prague in 2014.

Anna Šedivá
Prague, May 17, 2013

NEWS @

StemPAD study

A study on the outcome of transplant for antibody deficiency and CVID in collaboration with EBMT Inborn Errors WP and ESID BMT and Clinical WP.

Dear All,

Please find details of this important study from Freiburg on the outcome of transplant for antibody deficiency and CVID.

A letter explaining the study and the study questionnaire are attached below for download.

It is likely that there are only a few patients with these conditions that have been transplanted but its important to ensure that as many as possible are captured by the study.
Please address any queries regarding the study to Marta Rizzi marta.rizzi@uniklinik-freiburg.de

Kind regards
Bobby Gaspar
Chairperson ESID WP BMT

StemPAD_sketch_V1_2 (81k)

StemPAD questionnaire V1.2 (225k)

In Memoriam Claire-Michele Farber

Known by all of us for her knowledge in the field of immunodeficiencies and for her willingness to improve the health of immune-deficient patients, Claire-Michèle Farber passed away in Brussels on December 17th, 2012. She was born in 1953 and got her medical doctor degree from the Université Libre de Bruxelles in 1970 with a summa cum sum laude. She then became a paediatrician trained first in Brussels at the Cliniques Universitaires Saint-Luc and then during 2 years at the Memorial Sloan-Kettering Cancer Center in New York under the supervision of Prof R.A. Good. She came back to Belgium in 1982, where she spent her career at the Hôpital Erasme. In a pioneering effort she there created and developed the AIDS reference center of this hospital, which resulted in her being elected “woman of the year” in Belgium in 1992. Meanwhile, she got her PhD degree (Agrégée de l’Enseignement Supérieur). She then started to work also on the improvement of the diagnosis and treatment of patients with primary immune deficiencies (PID) and started to gather the Belgian physicians concerned by primary immune deficiencies, which eventually became the society now called the Belgian Primary Immunodeficiency Group. Since November 2012, this group is now officially recognized and is very active in taking care of patients with PID. Thanks to C.M. Farber, the awareness of PID among physicians in Belgium has drastically improved, and her willingness to diagnose as many patients as possible was transmitted to the young generation of Belgian pediatricians. In the name of the BPIDG and of all the patients she diagnosed and saved, we thank her for her devotion. She will be missed by all of us, and her death will be felt as a deep loss for all patients and physicians concerned by PID in Belgium and elsewhere.

The Belgian Primary Immune Deficiency Group