NEWS @ ESID

Newsletter Issue 3 | 2011

QUICK LINKS

In this Issue

ESID Summer School 2011 - Report
Read more

Participate in PedPAD study
Read more

Participate **in DOCK8 survey**
Read more

NEWS @ ESID

President's Corner

Dear Friends,

Well, the summer is over and I hope you enjoyed your vacation and are back at work with new ideas and discoveries.
Our plans towards the next ESID meeting in Florence are almost finished, thanks to the wonderful hard work Eleonora has done.

The program will cover the various aspects of our field and for sure it's going to be a very interesting meeting in one of the most beautiful cities!

As I wrote to you last time, the board met in Geneva and came up with several new priorities to our society. Hopefully, soon we are going to implant them, which will increase the awareness for PID!

ESID, which in my opinion, is the leading society in the world in the field of PID, is also supporting societies in Africa and Latin America for giving better care to patients with immunodeficiency all over the world.

Please mark in your calendar the date of the XV ESID meeting in Florence and hope to see you all there.

Amos Etzioni

Secretary's Corner

Dear ESID members,

Summer is over and the Executive Board is now ready to meet at the end of this month. As you can see in the following pages, ESID is presently organizing various scientific initiatives. A redifinition of the clinical criteria to be collected in the ESID registry is now needed. Stephan Ehl (University of Fribourg) is organizing a meeting at the beginning of December with the aim of restructuring the registry, based on the collective European experience over the last few years.

In parallel, many other events organized by ESID members but not financially supported by the society will be proposed. You can learn more by reading the report of ESID junior WP. In this regard, I would like to invite you to carefully read the report of the Educational WP about the success of the last ESID Summer School event.

Finally, I would like to remind you that this society can grow only with your comments and help. Although in every Newsletter I always complain that we need your suggestions and criticisms, I never receive any comments. Please e-mail me if you think that some things should change and how we can improve and better our Society.

I would also like to ask all of you to support our Society by convincing new members to join ESID. I would like to remind you of the benefits of ESID membership:

- Reduced registration fee to ESID biennial congress
- Access to a privileged network of PID professionals
- Eligibility to receive awards: travel grants, fellowships, publications
- Preference to take part in ESID PID Schools
- ESID Newsletter (quarterly)
- Access to ESID website members-only area

All the best
Anna

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Treasurer's Report

Dear all,

The XV ESID meeting in Florence, Italy (October 3 - 6, 2012) is approaching. We are only one year away! Considerable progress with regard to the organisation of the meeting since the first announcement has been made, and we are now much closer to the full picture.

The programme has been recently finalized and we are in the process to invite the speakers. Briefly, we will start with the traditional "Educational Day" on Wednesday October 3rd and, given the raising number of Junior members, we expect to have a lot of participants! Many activities are also "cooking" for ESID Juniors to involve more and more "the young power" in the society! The Opening Lecture will end the day and the official meeting will kick off. Thursday and Friday (October 4th and 5th) will be the "core" of the conference where the main topics will be covered during 3 parallel sessions, workshops and satellite symposium. Moreover, the conference will include contributed talks and poster presentations as always, but with a new entry, the "poster walks", where authors will have the opportunity to briefly present their work to a "walking" committee. Finally the conference will end on Saturday October 6th at lunchtime with late breakers and the Closing lecture to leave time for enjoying my beautiful city!
I am very excited to host you all in Florence and I am looking forward great science and interesting developments in PID! So…stay tune and visit the conference website for the latest news**(http://www2.kenes.com/esid2012/pages/home.aspx)!**

Eleonora Gambineri
Congress President

News: ESID Working Parties

Clinical

Dear all,
Update on current activities:

- **Development of SOP for diagnostic criteria in PIDD:** we had several rounds of email contact clarifying the purpose of diagnostic criteria and are currently discussing optimal formats in order to address heterogeneity of presentation without losing specificity.
- **Update on diagnostic criteria for CVID:** The next meeting of the participants will be held in Freiburg on the 3.12.2011. We hope to formulate a draft at this meeting which will be communicated to the members of the different societies before final decision and publication.
- **Case discussions online:** There is a great need of discussing difficult cases with colleagues. This might not always be possible at your site and therefore we all use email etc to involve experts from other centers. We have discussed the possibilities how ESID can support these activities. In order to avoid duplication of efforts we decided not to create another site for discussion but rather encourage you to join the existing email forum of CIS-PAGID**http://www.clinimmsoc.org/educational-resources/listservs**. The website will lead you through the process.

- **Diagnostic workshops:** As announced in our last newsletter, at the end of this week the first Diagnostic workshop for PIDD will be held in Freiburg. This time we address the German speaking colleagues and the great response confirms our feeling for a need in this area. If you plan any activity in your country please let us know we are happy to consider your application to endorse meetings focussing on diagnostics of immunodeficiency and support you with our experience. On the upcoming ESID biennial meeting in Florence we will focus the Workshop of the Clinical Working party on “Diagnostics in combined immunodeficiency”.
- **Financial support for clinical surveys/trials by ESID:** The decision on the procedure whether and how to support your ideas of clinical surveys and trials not only logistically but also by some funding eg to allow for investigator meeting etc, will be taken at the upcoming board meeting at the end of this month. Look out for new information on the ESID website. I hope that this initiative will facilitate increased activities in the field.
- **BCGitis in PIDD:** The survey has been closed and the data evaluated and are currently prepared for publication.
- **Immunosuppressive treatment in CVID:** The survey in four centers has also been closed; the data are currently evaluated and prepared for publication. The survey however clearly demonstrated the need for a prospective assessment of CVID patients treated with immunosuppressive therapy. Currently, this treatment seems to be based mainly on personal preference and varies dramatically between centers. While outcome is more readily measurable for treatment of autoimmune cytopenia, the real challenges are our approach to inflammatory lung and gut disease. These prospective data will be able to serve as the basis for future prospective interventional trials so urgently needed in this area.
- **New interventional trial in CVID STILPAD:** Through the German government we were able to receive a grant to run a double blinded study to analyze the potential of low dose steroid maintenance therapy to prevent progression of early interstitial lung disease in CVID. If you see CVID patients with changes in chest CT compatible with interstitial lung disease but without clinical symptoms and no alterations in the vital capacity in lung function at rest please contact me under Klaus.warnatz@uniklinik-freiburg.de to receive a synopsis of the STILPAD trial.

And finally:
It was the old Cato in Rome who ended all his speeches with the same statement so one day it will be heard:
I am still convinced that we all will benefit from increased cooperative activity like surveys and trials (quotation from the last newsletter and nothing has changed): Get involved, develop project ideas and support the activities of others in order to improve patient care. Please see also the website for current information.
Thanks to all of you who have supported this work,

Klaus

Education

Report – ESID Summer School 2011 in Barga, Tuscany, Italy

Dear ESID members,
We can look back upon another very succesfull ESID Summer School! Nine faculty members (Andrew Cant, Helen Chapel, Esther de Vries, Eleonora Gambineri, Steve Holland, Christine Kinnon, Mirjam van der Burg, Marta Rizzi & Klaus Warnatz) and 29 participants enjoyed a wonderful time at Il Ciocco Hotel & Resorts in Barga, Tuscany, Italy from September 28 to October 2, 2011. Unfortunately, 1 participant had to enter hospital unexpectedly on the day the Summer School started, and 2 faculty members had to be

replaced due to personal reasons.
The participants were very satisfied with the program content, the level of interaction with and support from the faculty, the level of interaction with the group, and the overall organisation of the event. They graded the Summer School an average 4.8 out of 5! All participants intend to pursue their career in Immunodeficiency.
We started on Wednesday afternoon with an introduction by Esther de Vries on awareness, diagnosis and classification, and by Steve Holland on inflammation and innate/adaptive interaction. On Thursday, basic and clinical aspects of antibody deficiency were presented by Mirjam van der Burg, Klaus Warnatz, Esther de Vries and Helen Chapel, and molecular diagnosis was explained by Mirjam van der Burg in the late afternoon. On Friday, Christine Kinnon gave an update of the developments regarding gene therapy for PID, and Andrew Cant discussed T-cell, combined and other well-defined immunodeficiency syndromes, and Eleonora Gambineri presented disorders of immune disregulation. In the late afternoon, Helen Chapel and Andrew Cant presented immunoglobulin and SCT treatment modalities.

On Saturday, Steve Holland discussed the defects in innate immunity, and Marta Rizzi updated everyone on ESID juniors activities. On Sunday, as well as on all the other days, participants presented their cases to the audience, and lively discussions always ensued.
The program was full, but their was also time for networking and relaxatation, during the early morning (breakfast, icy cold swimming pool), midday (lunch on the terrace) and evening (dinner and drinks). On Saturday afternoon, the whole party undertook a guided walk crossing the wooded mountain-side to the ancient little town of Barga, where we visited – among other things – the famous ‘Duomo’ that overlooks the Serchio valley. Saturday evening was spent at the Agriturismo I Cedri with wonderful Italian / Tuscan food and excellent live music. Despite the long days everyone still had enough energy to dance until midnight…
We hope to see all the participants again at future ESID activities, as active members in the field of PID!

’s-Hertogenbosch, the Netherlands, October 6, 2011,
Esther de Vries, Chair of the Educational Working Party

Join us on Facebook in the group ESID Juniors!
http://www.facebook.com/groups/esid.juniors/

All pictures of ESID Summer School now available!
https://picasaweb.google.com/elegambis/ESIDSummerSchool2011?authkey=Gv1sRgCPrR_L6Cyffg7QE&feat=email#

NEWS @

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. It is a really important issue in the field of primary immunodeficiency and only few of diagnostic centers have answered to this questionnaire.

The exchange of genetic diagnostic tools will improve the diagnosis and the genetic counselling of patients with PIDs which are important for the patients' support and care. Moreover, in the context of the technological advances in genomics, it is an exciting challenge to develop these new applications for the diagnosis and research of new PIDs. The ESID Genetics WP wants to be a link between clinicians, immunologists and scientists to help in the diagnosis of new PIDs and also to develop trials (i.e. on clinical and genetic correlation of specific PIDs). The Genetics working party closely collaborates with the other ESID working parties.

How to participate?
Please respond to the following questions:

Dear Colleagues,
We would like to be able to help direct our fellow ESID members when they have questions regarding laboratories that can be contacted for genetic testing of potential primary immunodeficiencies. In this regard, we would be grateful if you could answer the two questions below by return email (capucine.picard@inserm.fr):

- *Do you perform genetic testing for primary immunodeficiency diseases?*
- *If yes, for which genes are you performing tests?*

Thank you in advance for your response.

Our best,
Capucine PICARD for the Genetics WP of ESID

Registry

Stephan Ehl, Benjamin Gathmann

ESID Database Workshop

In the first half of 2011, we evaluated the experiences and results of the past eight years of the ESID Online Database project. This involved in particular a thorough check of the registered data for completeness, precision and validity. Many of the patient datasets show missing values for large parts of the current core dataset. Moreover, the disease-specific datasets are not sufficiently used and remain incomplete in most cases. The following reasons may contribute to this:

- The core dataset is too big and requires too much time to document
- The definition of several data items is incomplete or imprecise
- The core dataset is not driven by clearly defined basic epidemiological questions
- The disease-specific datasets are not driven by particular study questions (“nice to know” versus “need to know”)
- It is not evident to the users which scientific questions they help to answer with their data contribution
- Although there is substantial motivation to contribute to the registry, the current set-up does not make optimal use of this potential

In order to improve the data quality in the ESID Database, it is important that the experience of all national registries contributing to the ESID database is gathered and evaluated and a common perspective for our registry is developed.

Therefore, representatives of all national registries are going to meet in Freiburg on December 1-2, 2011 to develop a new core dataset. In addition, we will have invited speakers from SCETIDE, the European Registry for Stem Cell Transplants in Immunodeficient Patients (Paul Landais) and mitoNET, the German Registry for Mitochondrial Diseases (www.mitonet.org, Thomas Klopstock). The PPTA (Plasma Protein Therapeutics Association, www.pptaglobal.org) who are the main sponsors of the ESID Database, will also participate and present their perspective on the project.

Current status and publications

Recently, the French national reference centre CEREDIH published results from data on ataxia telangiectasia patients collected in the ESID Database born between 1954 and 2005:

Micol R, Ben Slama L et al. Morbidity and mortality from ataxia-telangiectasia are associated with ATM genotype. J Allergy Clin Immunol. 2011 Aug;128(2):382-9.e1. Epub 2011 Jun 12.

Romain Micol had presented this study at the ESID meeting in 's-Hertogenbosch in 2008. We are happy that it could be published in this high ranking journal.

For a complete list of all publications from the ESID Database, please go to:
http://www.esid.org/registry-studies-132-0

The current number of patients in the ESID Database is 14,650. This is an increase of more than 1,500 patients since the beginning of the year. In mid-2011, we transferred data from the national registries of

Spain and Italy and the local databases in London and Newcastle to the ESID Database. The UK is now running a copy of the ESID Database on local servers in London. There are regular data transfers between the two systems.

For more statistics, including our well-known "map of Europe", please visit:
www.esid.org/registry-number-of-patients

ESID Juniors

ESID Summer School

We had a great summer closed by the ESID Summer School: twenty-nine Juniors and 9 faculty came together in Barga Tuscany in the beautiful hotel Resort Il Ciocco from the 28th to the 2nd October 2011. We the expertise of the faculty we were able to cover almost all aspects of immunodeficiency: diagnostic protocols and clinical presentations Esther de Vries, antibody deficiency and its molecular causes in adults and children with Helen Chapel, Klaus Warnatz, physiology and pathology of innate immunity with the description of the last new gene defects discovered in the field with Steve Holland, T cell deficiencies and bone marrow transplantation with Andrew Cant, immune-disregulation with Eleonora Gambineri, B and T cell development and molecular diagnosis of primary immune deficiencies (PID) with Mirjam van der Burg, gene therapy in PID with Cristine Kinnon.
The ESID summer school fulfilled all the requirements that a Junior activity should have, it has been **educational** with great lectures and lively exchange over the interesting cases proposed by the students. **Interaction** between Juniors and faculty was great during the session but also in the free time, helped by the very remote and private location of Il Ciocco. We were able to **exchange** our experiences over work research career. Very important for Juniors it has been a wonderful occasion for **networking** to find colleagues with same or diverse interests. Last but not least we had a great time, we had beautiful sunny weather for the whole week, and we had a very nice walk from Il Ciocco to Barga through the Tuscan hills with beautiful view over old houses. We also visited Barga, an old Florentine domain in the province of Lucca, with a breath-taking cathedral, the first version of which was from 1100. The night of Saturday we had a great dinner in Albiano a small village close to Barga with Italian food, good wine and live Jazz music and dancing at the end. Juniors and faculty could interact in a great location with beautiful view.
The best way to describe the ESID Summer School is to listen to the opinion of the participants, therefore I asked to some of them to write a short impression over their experience. Here you have them.

Alexis Cochino (Romania)

I write this against my will!...I am only joking, of course!
Marta asked me to tell you how the ESID summer school was and I feel this is not in my best interest…as when I will tell you how a marvellous experience that was, you will all apply for the next winter, spring and summer ESID schools and I will have not the slightest

chance of going there again!
Well, let's start with faculty: I suppose that, from previous ESID meetings, you all do know Helen (Chapel), Andrew (Cant), Esther (de Vries), Steven (Holland), Klaus (Warnatz), Eleonora (Gambineri), Mirjam (van der Burg). What you may not know is how fascinating their lectures can be in an ESID school setting! How stimulating their discussions, how brain-storming their questions, how helpful their real-life case scenarios! Specific topic lectures were intermixed with cases presented by the students, pointed by targeted questions, both from the faculty and the students, frequently leading to long and cerebral waves-boosting discussions!
Even though the sessions were day-long (8 A.M. – 7 P.M., and even more) and we were having scientific discussions even during lunch-break (poor faculty members never got to eat right because of our many, many questions!), I never felt tired or bored!
We also tried to know each other, our work, our problems and our projects, creating a network for the future; many research ideas are based on this exchange.
All of this happened in a wonderful setting, Tuscany, and ticked like good clockwork, thanks to Marta, Esther and Susanne!
Thank you, ESID!
P.S. Don't rush for application! It is not yet open…

Vera Goda (Hungary)

We had a wonderful but very busy program on all sorts of PID with experts who did not just present their up to date results on their fields but really wanted to hand over their knowledge and gave practical advices all day. Esther started with a breezy giving of basic knowledge for diagnostic approach so we could get going with the cases later, Mirjam was all smiles and it also helped us understanding genetic analysis. Klaus taught us not only with his experience but how to ask good questions. Helen is an icon for many of us with her comprehensive knowledge, Andrew and Steve can pass their experiences in a way you can never forget, Christine and Eleonora also gave very useful syllabi from their fields…so as a summary: we learned a lot and had great fun!

Jana Semberova (Slovak Republic)

I appreciated very much the opportunity to participate to the ESID Summer School this year. The event was placed in a wonderful countryside of Tuscany in Italy and we had the chance to be educated in the field of primary immunodeficiency by excellent speakers. The program had a good structure both for clinicians and for scientists working in the laboratories as well. Our cases were presented in an interactive setting, so that everybody had the opportunity to discuss the diagnostic or therapeutic opportunities for our PID patients.
I have met a lot of nice people from all around the world and I hope we will keep in touch for the coming years.

Francesca Ferrua (Italy)

ESID SUMMER SCHOOL 2011: an exceptional opportunity to dive into the deep of the PID world, to meet and interact with experts in the field, to share experiences and build up networks with friends all over Europe and beyond! A mind opening experience of inestimable value that I strongly suggest to all the people who are entering the PID community!

Amit Rawat (India)

It was an enriching and intellectually invigorating experience for me as a participant in the ESID summer school 2011 in the pristing hills of Barga, Italy. I had a golden opportunity to learn from the vast experience and expertise of the stalwarts and luminaries in the field of Primary Immunodeficiency Diseases (PIDs) from both Europe and US. It was also a great platform for interaction with peers and colleagues from the clinics, labs and research arena at the common forum at the same time. I would like to felicitate and thank the members of Working Party Education of ESID for this thoughtfully planned and efficiently executed event. I hope to keep in touch with the other participants from different parts of the globe and also with the august faculty in the years to come.

As result of the discussion we had at the Summer School, we decided to start a facebook group called ESID Juniors, it will be a platform where we can exchange information, interesting papers, experiences, and keep in touch. This group will be accessible only to ESID members (Juniors or Seniors). The list of

participants will be public but the content will be available only to members. So if you are in facebook look for ESID Juniors and join the community there. At the moment you can enjoy the picture of the Summer School 2011! It will be a great tool to develop new ideas!

Remember the 15th of November is the dead line for 2 short term ESID fellowships. You can use our map of centers (ESID Junior page in the ESID website) to look in the available centers to plan something that can help you develop your career and knowledge in PID!

I wish you all a great start after the vacation time, and keep in touch!

Marta Rizzi
Junior WP Chair

Young Researcher's Corner

DETECTING PROTEIN PHOSPORYLATION AND CELL SIGNALING BY FLOW CITOMETRY

Phosphorylation of proteins is an important reversible regulatory mechanism of post translational modifications that occurs in both prokaryotic and eukaryotic organisms due to enzymes called kinases (phosphorylation) and phosphatases (dephosphorylation) that regulate intracellular protein phosphorylation in many different cell signaling pathways (T and B cell signaling, those regulating apoptosis, growth and cell cycle control, those involved with cytokine, chemokine, and stress responses). Reversible phosphorylation results in a conformational change in the structure of many proteins that become activated or deactivated. In eukaryotic proteins phosphorylation usually occurs on serine, threonine, tyrosine and histidine residues. The addition of a phosphate group (-PO32-) to a polar R group of an amino acid residue introduce a conformational change in the structure of the protein turning a hydrophobic portion into a polar and hydrophilic portion of molecule that interact with other hydrophobic and hydrophilic residues in the protein. Upon the deactivating signal, the protein switches back to its original conformation.

Janus tyrosine kinase (JAK)-Signal Transducers and Activators of Transcription (STAT) signaling pathway is one of the major cell signaling mechanism and it is important in transmission of information from chemical signals outside of the cell, through the cell membrane, and into gene promoters on the DNA in the cell nucleus causing DNA transcription and activity in the cell.
Signaling through the JAK/STAT pathway begins at the cell membrane when specific cytokines bind their target receptor. This triggers the autophosphorylation on tyrosines of non-covalently attached JAK kinases, which also phosphorylate signature tyrosine residues in the intracellular receptor tails thus providing sites for interaction with phosphotyrosine-binding SH2 domains located on STAT proteins. The bound STAT monomers are themselves phosphorylated by JAK on a single tyrosine residue at their COOH terminus inducing the detachment from their receptor docking sites and the formation of high avidity reciprocal homo- or heterodimers. This sequence of events (STAT activation) triggers the accumulation of STAT dimers in the nucleus where they can bind to palindromic DNA recognition sites (GAS) and directly induce transcription (Fig. 1).

In human there are seven STATs (STAT1, -2,-3, -4, -5a, -5b, -6) and they are expressed in multiple cell types, are activated by many growth factors such as growth hormone, prolactin and cytokines, and paticipate in a diverse set of biological activities. They are greatly evolutionary conserved and their mutations, disruption or dysregulated functionality (which is usually inherited or acquired genetic defects) can result in cancers and immune deficiency syndromes (i.e STAT1 deficiency, hyper-IgE syndrome, STA5b deficiency).

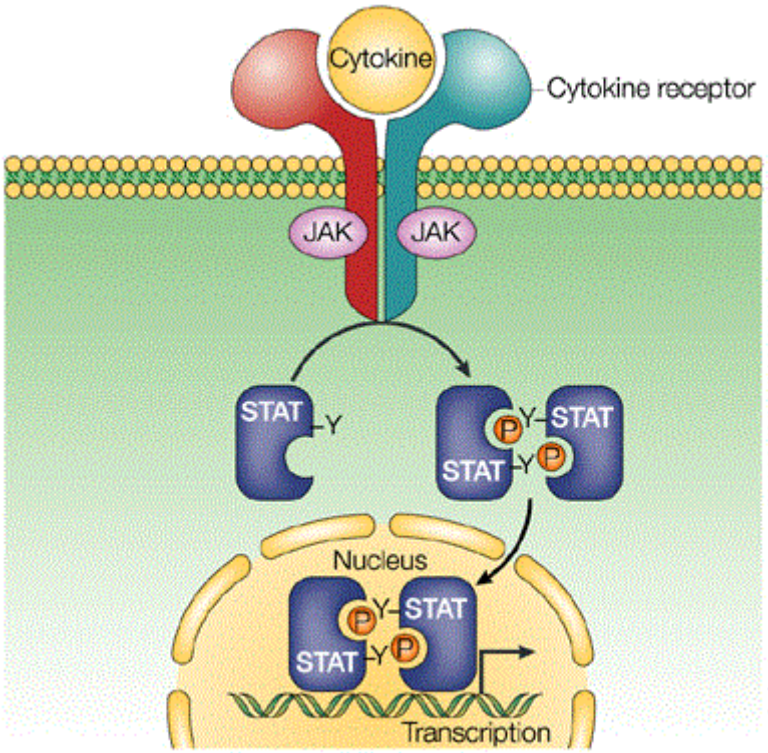

Fig. 1) A schematic representation of the JAK–STAT pathway. (Modified from K. Shuai & B. Liu, 2003)

In the past phospho protein detection has been performed with techniques using radioactivity as radiometric kinase assays and phosphoaminoacid labeling. However, the advent of phospho specific antibodies has facilitated the use of more straightforward techniques such as western blotting, ELISA, immunoprecipitation, and immunofluorescence microscopy. These techniques, however, have several shortcomings as they require a relatively large amount of sample, are time consuming, do not produce truly quantitative results and are not conducive to multiparameter analysis.

Flow cytometry is advantageous because it allows rapid, quantitative and single cell analysis. Proteins can be detected in a specific cell type within a heterogeneous population via cell surface marker phenotyping without the need to physically separate the cells. In this way, a small, rare population of cells may be analyzed without concern for cell loss or altered protein expression that may occur during a cell-sorting process.

Detection of phospho proteins by flow cytometry requires that the protein is stable and accessible to the antibody. Cells or whole blood can be used for the analysis. First of all the sample is stimulated with specific mytogens depending on the pathway of cell signaling where the phospoprotein is involved in (i.e. IL2 activate phosphorylation of STAT5). Cells stimulation is a critical step of this process because phosporylation is influenced by the type of cells and stumuli, the time of stimulation and concetration of mytogens. Immediately after stimulation cells are fixed with formaldehyde or paraformaldehyde to cross-link the phospho proteins and stabilize them for analysis. Cell staining before fixation is not recommended because it could activate cells in an unspecific way alterating the phospho protein phosporylation state. The fixed cells must be permeabilized to allow the entry of phospho-specific antibodies into the cell. Different permeabilization techniques are often useful for various subcellular locations. A mild detergent will allow the detection of cytoplasmic proteins, while alcohol may be required for antibody access to nuclear proteins. Alcohol permeabilization may also enhance phospho protein detection using peptide specific antibodies due to the denaturing property of alcohol. Then cells are stained at the same time with fluorophore-coniugated antibodies binding the phospho protein and the superficial markers, washed,

acquired with the flow cytometer and analyzed as a classical multiparametric analysis. The positive percentages represent the quantity of cells that show phosporilation of the specific protein or the percetages of activated cells responding to the specific stimulation. The pecentage of positivity needs to be evaluated compared with the not stimulated negative control.
This method is a powerful tool to study downstream signaling in T and B cells following respectively TCR and BCR activation and in response to specific stimuli, evaluating which signaling cascates is activated, the kinetics of signaling and the downstream target that are transcribed. Moreover, comparing diseased cells to healty samples, it is possible to identify aberrant signaling, changes in key phosphotyrosine residues and analyze the effect of a mutation in the phospho protein.

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Sara Ciullini Mannurita

PID Care in Development

Summer is seemingly “cucumber season” in the ongoing process of increasing awareness about PIDs. The period is traditionally devoted to the organization of summer schools. A preparation of ESID summer school 2011 is finishing these days and the school seems to be a great success, as usual. You can find report on ESID summer school **Here**

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The J project series of meeting with the goal to increase an awareness of PIDs in Central and Eastern Europe goes further East to China this summer and underlines its tremendous importance for increasing awareness about primary immunodeficiencies – for details see separate article in Newsletter.
ESID PID in Development WP is also in charge with EU related activities. During summer months, the “2011 Report on the state of the art of rare disease activities in Europe of the European Union Committee of Experts on rare diseases“ was released.
Report is available here **http://www.eucerd.eu/**. The report does not deal directly with PIDs, it, however, forms the base for the strategic negotiations with EU in the promotion of PIDs related issues in European countries. Particular discussions with EU officials are planned for December this year. Any comments, questions and suggestions for such talks are welcomed.

Anna Sediva,
Prague, September 27, 2011

NEWS @

PedPAD study

We would like to invite you to participate in the PedPAD Study concerning **Clinical and laboratory characteristics of children with hypogammaglobulinemia as documented in the ESID online Registry**.

Most of the currently published clinical data on hypogammaglobulinemia concern adult patients; because of their maturing immune system, these data cannot simply be extrapolated to children. An overview of pediatric data will be helpful for doctors caring for these patients, and may form the basis for further clinical studies.
We want to use the data collected in the ESID Registry to give an overview of all clinical, laboratory and geographical features of children with hypogammaglobulinemia, and describe possible diagnostic delay. Please let us know whether you want to participate with the data from your centre.
Please download the invitation letter and the study protocol for more information.
Dr. Esther de Vries
June 2011

Return to Newsletter

PedPAD Invitation letter (51k)

PedPAD research protocol (347k)

DOCK8 deficiency therapy survey

On behalf of our working group we kindly invite you to join our survey.
Online submission via the ESID Database is now open!

The data forms are available both in the subregistry **DOCK8 (Combined ID)** and **Hyper IgE syndrome (HIES)**.

In addition, submission on paper is also available.

Please find more information in the invitation letter.

We are looking forward to your help!

The DOCK8 Working Group

Mail contact: Ellen.Renner@med.uni-muenchen.de

DOCK 8 Invitation letter (34k)
Version 2011-03-30

DOCK 8 Case Report Form (40k)
Version 2011-12-21