

ESID Newsletter

Contents

Introduction	2
ESID information	3
President's letter	4
Treasurer's report	4
Secretary's report	5
News & Views	5
Evaluation of the J-project	5
Working Party reports	8
Registry WP	8
Clinical WP	10
Focus on a country: Serbia and Montenegro	11
Educational Working Party: € 10,000 Scholarship, <i>the winner</i>	14
Announcement ESID Summer School 2005	15
Application form ESID Summer School 2005	16

The ESID Newsletter is made for the members of ESID - the European Society for Immuno Deficiencies.

It is published under the responsibility of the ESID Board, and at this moment it is edited by Esther de Vries.

Any ESID member who is interested in publishing his or her views, research, new ideas or other material in the ESID Newsletter is cordially invited to submit copy to the Editor. Suitability for publication is assessed by the Editor in consultation with the other members of the ESID Board.

Editor's address:

Dr. Esther de Vries, pediatric immunologist, Jeroen Bosch Hospital loc GZG, P.O. Box 90153, 5200 ME 's-Hertogenbosch, the Netherlands, tel. +31-73-6992965, fax +31-73-6992948.

**PLEASE NOTE !!!
email has changed
into:
dr.estherdevries
@tiscali.nl**

*Front page:
Goldfish in my pond in
early spring.*

Dear ESID members,

Close to the summer holidays, you find another ESID Newsletter in your mailbox. The latest developments of the ESID Registry, the field of immunodeficiency in Serbia-Montenegro, the winner of the ESID Scholarship this year, and more ... You will find it all inside.

Most likely, you will not find a contribution of yourself among these pages, and that is a sad thing! Too few ESID members use the ESID Newsletters to have contact with each other. You don't have to be a senior researcher, honorary member, or head of a big staff to publish in the ESID Newsletter! On the contrary, we welcome contributions from *any* ESID member on *any* subject that concerns immunodeficiency research and/or patient care. Please send me your interesting patients, reviews on your favourite subject (please consult me before doing a lot of work), impressions of meetings, points to discuss, etc. etc. **The e-mail address is dr.estherdevries@tiscali.nl .**

Please have a look at the last pages which contain the information and application form for the ESID Summer School. Don't hesitate to apply, or to suggest to others to do so. Participants have always been very enthusiastic about the ESID Summer Schools, so make sure you've been there some time if you want to belong to the European 'immunodeficiency world'.

Best wishes to all of you,

Esther DE VRIES, Editor



ESID is the European Society for Immunodeficiencies. It was formed in 1994. The forerunner of ESID, the informal European Group for Immunodeficiencies (EGID) was established in 1983. Anyone who is interested in primary immunodeficiency diseases can become a member of ESID. You can find the necessary information to contact the treasurer Esther de Vries at www.esid.org.

Within ESID, six Working Parties are actively engaged in coordinating the member's joined efforts in patient care and research in primary immunodeficiency diseases: Bone marrow transplantation (chair: Mario Abinun), Patient registries (chair: Bodo Grimbacher), Clinical (chair: Bobby Gaspar), Genetics (chair: Anna Villa), Education (chair: Anders Fasth), and ESID *juniors* (chair: Pim van der Vossen). Anyone who is interested in participating in one or more of these Working Parties is invited to do so. Please contact the chairman of the relevant Working Party (contact information is available at www.esid.org).

In 1994, a main registry of patients with various forms of immunodeficiency in Europe was established. Altogether, data from some 10,000 patients from 26 countries were received until now. In 1995, the first locus-specific immunodeficiency mutation database accessible through the internet was established (BTKbase for X-linked agammaglobulinemia - curators Mauno Vihinen and C.I. Edvard Smith). Since then, several additional locus-specific data bases have been established: ADAbase (adenosine deaminase deficiency - curators Mauno

Vihinen and Michael Hershfield), BLMbase (Blooms syndrome - curator Mauno Vihinen), CYBAbase (autosomal recessive p22 phox deficiency - curators Dirk Roos and Mauno Vihinen), CYBBbase (X-linked chronic granulomatous disease (XCGD) - curators Dirk Roos and Mauno Vihinen), CD3Ebase (autosomal recessive CD3 epsilon deficiency - curators Mauno Vihinen and Jose R. Regueiro), CD3Gbase (autosomal recessive CD3 gamma deficiency - curators Mauno Vihinen and Jose R. Regueiro), CD40Lbase (X-linked hyper-IgM syndrome - curators Luigi D. Notarangelo and Mauno Vihinen), JAK3base (autosomal recessive severe combined JAK3 deficiency - curators Luigi D. Notarangelo and Mauno Vihinen), NCF1base (autosomal recessive p47 phox deficiency - curators Dirk Roos and Mauno Vihinen), NCF2base (autosomal recessive p67 phox deficiency - curators Dirk Roos and Mauno Vihinen), RAG1base (autosomal recessive severe combined RAG1 deficiency - curators Mauno Vihinen and Anna Villa), RAG2base (autosomal recessive severe combined RAG2 deficiency - curators Mauno Vihinen and Anna Villa), SH2D1Abase (X-linked lymphoproliferative syndrome (XLP) - curators Luigi D. Notarangelo and Mauno Vihinen), TCIRG1base (autosomal recessive osteopetrosis (arOP) - curators Mauno Vihinen and Anna Villa), ZAP70base (autosomal recessive severe combined ZAP70 deficiency - curator Mauno Vihinen), WASPbase (Wiskott-Aldrich syndrome - curators Mauno Vihinen and Luigi D. Notarangelo) (information is available at www.esid.org).

ESID organizes a biennial congress to facilitate international contact between primary immunodeficiency specialists. The last congress was organised in 2004 in Versailles, France; the next congress will be organized in Budapest, Hungary in October 2006, and the one after that will be in The Netherlands, in 2008.

= ESID Information =

President's letter

Immunodeficiency and training

Dear friends,

One of ESID's main activities during the last five years has been to favor education of young clinicians in the field. The ESID Summer (and Spring) school and the ESID Educational day (the day before the last two ESID Meetings) have been the way how this initiative has been substantiated. Many good reasons support this effort, in particular the need to attract new investigators to the field. Moreover, particularly during the ESID Summer School, Helen Chapel and after her Anders Fasth have tried to favor integration of different clinical expertise among participants (so that a clinician with a previous experience in Gastroenterology may sit aside another clinician with an experience in Hematology). Clinical Immunology, after all, is a transversal Specialty; as such, it is good that different clinical disciplines be integrated when discussing and preparing Educational Workshops in Primary Immune Deficiencies. The success of these initiatives is well known to everybody, and has been discussed many times on these pages as well. Even the fact that an ESID *junior's* Working Party has been started recently is a good demonstration of the outcome of these efforts.

While it is very important that the ESID Schools go on, and that more Educational Days be organized at the time of ESID Meetings, I believe ESID must take additional initiatives to favor training. In particular, I am convinced of the importance to organize, at the European level, a training program in the field of Clinical Immunology. Andrew Cant has been directly involved in this effort. To this purpose, he has also taken advantage of his dual role in ESID and ESPID (European Society of Pediatric Infectious Diseases), of which many other ESID colleagues are a member as well.

Indeed, there is a strong need to build up a training program in Clinical Immunology at the international level. Primary Immune Deficiencies (PID) should represent a core area of interest in such programs. Therefore, ESID should play a role in the harmonization of training programs in PID. The recent call for exchange fellowships, launched by Anders Fasth in the latest issue of the Newsletter, is another example of how important international collaboration and advanced training is for the ESID Board. In addition to that, it is perhaps time to go beyond simple and individual membership, and rather to create a database of services and training programs currently available at all major centers that deal with PIDs in Europe. Listing and advertising available positions through the ESID Newsletter might be another good thing to do. Comparing training programs in force at the various centers would be a further step towards a shared European dimension. Perhaps, the possibility of a PhD program in Primary Immune Deficiencies based on a European Network is not too far....

I would greatly appreciate to hear your opinion and suggestions!

Luigi NOTARANGELO

Treasurer's report

There are still some missing addresses, please help me out if you know any of these:

Strobel, Datkova, Pellier, Berglöf, Kidon, Dupuis, Nieto Diaz, Kanegane, Oksenhendler, Carneiro-Sampaio, Cristina, Andresen, Schmidt, Schütz, Kurenko-Deptuch, Mori, Nothers, Dos Santos-Guedes.

By now, 298 of the 403 members in the database have paid their ESID

membership fee 2004-2005. Unfortunately, that means *105 people* have *not*! They will now receive their last reminder, and must again do without a copy of the ESID Newsletter. Do you know of anyone who wonders why they don't get the ESID newsletter anymore? Please explain to them they are probably behind in payment, and urge them to set this right!

Secretary's report

During the last ESID Board meeting, it was decided to move the management of the ESID internet website to Freiburg, Germany. The ESID Board very much appreciated the efforts and achievements of Mohammed Abedi, the former ESID webmaster, for creating an informative and well-designed website. With input from the new ESID *juniors* working party, Bodo Grimbacher will be in charge of maintaining the ESID website from now on, thus providing an up-to-date forum of information for all ESID members. **Suggestions from ESID members regarding new features for the website or improvements of existing sections are highly welcome!**

Following a report about the ongoing progress of the ESID online patient registry, it was decided that in the future a quarterly update of the status of the patient registry and already existing subregistries will be published in the ESID Newsletter.

In addition, at the last ESID Board meeting a new ESID fellowship research grant was created. It will be issued through the Educational Working Party for one ESID junior member every year.

The next ESID Board meeting will take place in Budapest, Hungary, on June 15. **If you have anything in mind that the Board should discuss, please let us know!**

Hermann WOLF

News & Views

Evaluation of a pilot experience to raising the awareness of PID in Primary Health Care Centers.

I am Javier Carbone of the Immunology department of the University Hospital Gregorio in Marañón, Madrid, Spain.

The Clinical Immunology Unit of our Hospital in the Community of Madrid recently initiated an educational program to raise awareness of primary immunodeficiencies.

As a part of this program, we organized an educational visit to a Primary Health Care Center. The educative methodology included a formative session (2 hours), discussion, and a questionnaire at the end of the session. The first concurrent session included basic concepts of the diagnosis and treatment of PID. Eleven family doctors, two pediatricians and one internal medicine specialist of the "Federica Montseny" Primary Health Care Center attended the session. These doctors attend a population of over 20.000 children, adolescents and adults.

Evaluation of the questionnaires revealed that 9 out the 14 doctors (64%) recognized to have at least one patient with warning signs of a possible PID! Five out of the 14 (36%) indicated that they had a patient diagnosed with a primary antibody deficiency [Selective IgA deficiency (n=3) and Common Variable Immunodeficiency (n=2)]. This observation shows the importance of Primary Health Care Centers as a focus of attention and action within awareness campaigns for the diagnosis of PID.

We think this experience can be useful to others, and hope other ESID members will pick up the challenge of focussing on Primary Health Care as a way of increasing the awareness of PID!

Javier CARBONE

*Extended J-project meeting, April 16, 2005,
Sofia, Bulgaria*

The Extended J-project meeting was held in Sofia, Bulgaria on April 16, 2005, in the Central Hall of the Forum Hotel, situated near the Medical University of Sofia. It was organized by the Central Laboratory for Clinical Immunology, together with the Department of Pediatrics of the Medical University Hospital "Alexandrovska", Sofia. The meeting was attended by more than 50 immunologist and pediatricians from all over the country. Doctors from East-Central Europe attending the meeting were: Prof. Laszlo Marodi and Melinda Erdos from Debrecen, Hungary; Beata Wolska-Kusnierz from Warsaw, Poland; Alla Volokha from Kiev, Ukraine; Mihaela Bataneant from Timisoara, Romania; and Prof. Sonja Peova, Katarina Stavric and Lidija Kareva from Skopje, Macedonia.

The main task of the Extended J-project meeting in Sofia was to exchange knowledge and experience in PID diagnosis and treatment. Report on the activities of the national registries and a discussion on the establishment of a network for molecular genetic diagnosis of PID was intended.

The first presentation was given by Prof. L. Marodi. He talked on the purpose of the Extended J-project and summarized the future tasks of this initiative. An overview on the clinical criteria of PID, differential diagnostic approach in Bulgaria and their frequencies was presented by Prof. Ilia Kalev. Prof. Elissaveta Naumova presented the diagnostic algorithm used routinely for PID suspected patients in the Central Laboratory for Clinical Immunology. ESID - registry, grants, diagnostic and therapeutic guidelines were explained in details by Dr. Beata Wolska. Extensive information on IVIG treatment in East-Central Europe, was given by Alla Volkha. The problems regarding this type of treatment in Bulgaria have been discussed, and a necessity of a national policy on IVIG treatment arose.

Next session topics were targeted

mainly at the PID registries in the countries of the participants. Dr A. Volkha, Dr. B. Wolska, Prof. S. Peova and Dr M. Bataneant gave very detailed presentations proving that the J-project initiative works and gives good results

Dr. G. Petrova in a very attractive way presented the first steps of the Bulgarian registry and current problems in PID patient registry development in Bulgaria. With enthusiasm, she assured the participants that Bulgarian pediatricians will work hard in the near future to achieve the results of their colleagues. And they relay, certainly, on a collaboration with colleagues from the other East-Central European countries as well as on a grant from the Jeffrey Modell Foundation.

In the afternoon session, there were several very nicely presented case reports with WAS (Dr. D. Popova), AT (Dr. V. Cvetkova), hyper-IgM syndrome (Dr. M. Erdos), IgA-deficiency (Dr. E. Savov), MHC class-II deficiency (Dr. D. Baltadjieva) and hereditary angioedema (Dr. P. Krastev). Along with this, the diagnostic problems and participants' experience was discussed. Dr M. Bataneant from Rumania talked on the clinical manifestation of autoimmunity in children with PID.

At the end of the meeting, a concept for establishment of a network for molecular genetic diagnosis of PID in the region was presented by Dr. D. Baltadjieva. This was supported also by the idea of Prof. L. Marodi who suggested that a meeting should be organized in the near future between representatives of the centers which have already developed molecular-genetic testing for PID: Debrecen is able to detect mutations of 6 PIDs - XLP, HIGM1/2, WAS, SDS, XLA and CLCM, Sofia - of 4 genes involved in MHC class-II PID, Zakopanje - of AT and NBS genes. This initiative has been accepted as a good idea for sharing the burden of genetic analysis of PID's between the different countries.

The meeting was closed by Prof. E. Naumova and Prof. L. Marodi, and the guests

visited the Central laboratory for Clinical Immunology at the Medical University "Alexandrovska"-Sofia. The Laboratory was founded in 1971. Since 1998 the laboratory has been accredited by the European Federation for Immunogenetics and since 2000 has been chosen as National Reference Laboratory for tissue typing and immunological monitoring by the Bulgarian Ministry of Health. The main directions of diagnostic and research work are in the field of immunogenetics, transplantation, autoimmunity, allergy, immunodeficiencies and malignancies. The most recent technology in molecular biology and flowcytometry is used in any of the directions. The laboratory is participating in several international and national research projects.

I do believe that the Extended J-project meeting in Sofia was a very successful one, not only because it contributes to achieve the purpose of the project. As a final step of the meeting a decision for organizing a molecular genetic diagnosis network for PID was taken which will develop in the future under the coordination of Prof. Marodi.

Elissaveta NAUMOVA

A booklet has been printed that contains the programmes and summaries of the previous J-project meetings. This was sponsored by ECE IPI CTR.

If you are interested in knowing more about the (extended) J-project, please contact prof. László Maródi from Debrecen, Hungary.

Some impressions of Budapest, Hungary:



where the next ESID meeting will be held



from October 5 to 8, 2006,



organized by László Maródi.

Working Party reports

Registry Working Party

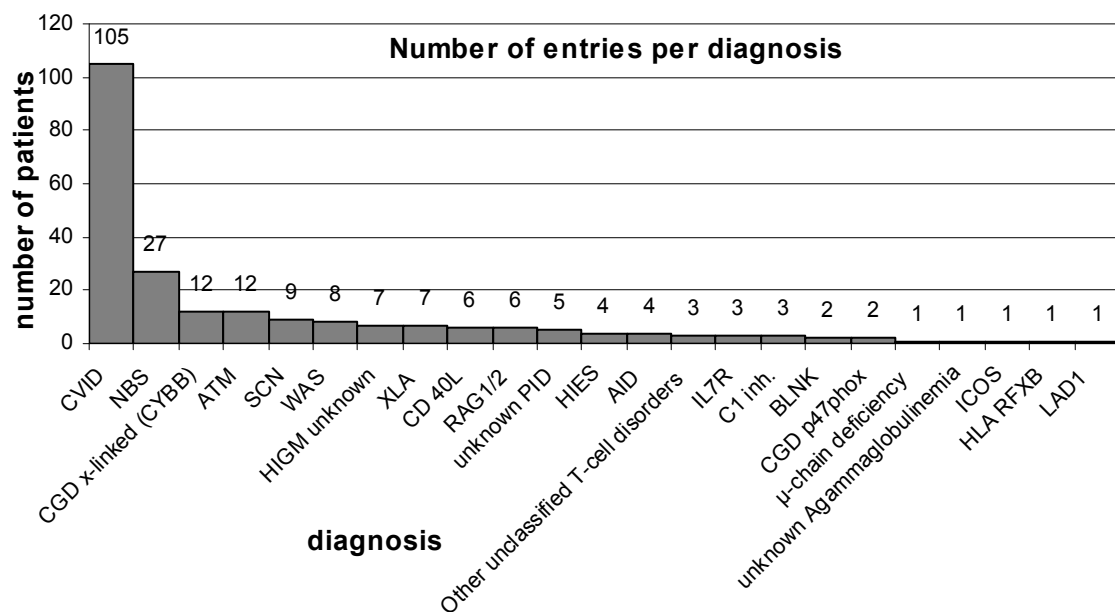
First of all, we would like to inform you about the state of our online registry. The total number of registered documenting centers is now 46, situated in 24 different countries. Fortunately, the number of patients in the registry has increased substantially within the last months. By the end of March, 231 patients have been documented by 19 documenting centers that have already started entering their patients. The following subregistries are already completely activated, for all others the common core dataset is available: CVID, Secondary Hypogammaglobulinemia, DiGeorge syndrome, Hyper-IgE syndrome.

The 231 patient datasets entered into the ESID online registry cover a whole range of primary immunodeficiencies, as is illustrated in the Figure below. This indicates that things are really getting started now. In this regard, we would once again like to

remind you of the compensation of 10 Euro paid by the sponsors of the online registry for every patient dataset covering the "red fields" of the core dataset by June 30th 2005.

In addition to this, we now offer an extra bonus of 2.000 Euro for the first 15 documenting centers to register 50 patients with complete "red fields" until August 1st 2005. Since many documenting centers assign a lack of time and manpower as their main problem, this might be a little compensation for the extra work to be done.

Quite recently, our team here in Freiburg has grown. Three new collaborators are now working on the ESID project. Viviane Knerr and Benjamin Gathmann will be your contact persons for almost all questions. The email address frisch@medizin.ukl.uni-freiburg.de will, however, remain the same. The respective new email-addresses are: Gathmann@medizin.ukl.uni-freiburg.de and Viviane.Knerr@uniklinik-freiburg.de. They will also forward your questions concerning ethics and data protection to Dr. Anne-Marie Eades-Perner who will be in charge of these topics.



During the last weeks, we have conducted an email survey among the documenting centers in order to find out whether the centers have difficulties in registering their patients, and if so, to find out what these difficulties are. Most centers indicated that they are willing to work on the documentation of their patients, but unfortunately very often time is lacking. But we also found out that obtaining ethics and data protection approvals causes problems for several centers. If this should be the case in your center, please don't hesitate to contact us for support. We will provide you with documents that might be helpful for your local committees. Other centers mentioned technical problems as their main handicap and were uncertain whether their security facilities were sufficient. In fact there is no need for a firewall in your center, because the system is running behind a firewall here in Freiburg. Thus you can go ahead and start documenting right away, without having to invest in a firewall system.

We are very glad to say that the European Union supports the setup and maintenance of the ESID online registry. Therefore, the ESID registry is now part of the 6th Framework Program of the European Community. The program has been termed EU-POLICY-PID and is organized by Edvard Smith and Anna Berglöf in Stockholm. The aim of the registry within the program is to establish European guidelines and procedures for setting up clinical patient registries. The results of this project are expected to help the ESID online registry a lot, since we are currently dealing with more than 50 different local ethics committees and data protection officers. In order to better meet the demands of data protection, the patient consents in German language have been slightly modified. You can download the documents from the ESID website. An English translation will be available soon.

In the future, we are planning to offer and establish a "2-server-solution" which will allow the treating and documenting physician to view the patient's name which is stored on

a separate server. This concept has been previously approved by the Telematic platform. The solution demands a strict spatial separation of the server storing identifying patient data and the second server storing therapy data. Thus, data protection is absolutely guaranteed. However, the treating physician (and only him or her) will be able to combine data from both servers on screen by entering the correct password. We will probably be able to offer this solution by the end of this year. Another novelty will be the ESID Mutation Detection Tool, which is a multicomponent system for the deposition of mutation data. It directs the user via a SSL-encrypted connection to the "IDbases"-database in the Institute of Medical Technology in Tampere, Finland, created and maintained by Mauno Vihinen. There, the gene mutation event is deposited and validated with "Bioinformatics"-tools and automatically submitted back to the ESID Mutation Web Service, which matches the validated data with the ESID online registry. The exchanged data contain no personal patient information, thus the data received in Finland are anonymous.

Currently, this tool works with genomic DNA and cDNA and includes information related to homozygosity and number of the affected alleles where applicable. The tool support is planned to be extended to approximately 90 subregistries.

If you have any suggestions, questions or demands, please feel free to contact us at any time. We will be glad to answer your questions and to support your work.

Bodo GRIMBACHER

Clinical Working Party

It is a pleasure to introduce myself to you as the new Chairman of the Clinical Working Party of ESID!

I am a physician/scientist working in paediatric immunology at the Institute of Child Health (ICH) and Great Ormond Street London. I initially trained in paediatrics, and then became interested in primary immunodeficiencies at an early stage in my career and undertook a PhD with Christine Kinnon at the Molecular Immunology Unit at ICH. From there, I have continued my academic and clinical career. My interests are in many different aspects on primary immunodeficiency, including understanding the molecular and cellular defects and disease pathogenesis, bone marrow transplantation for severe immunodeficiencies, and the development of gene therapy for these conditions. Recently, with my close colleague Adrian Thrasher, we have shown that the immune defect in SCID-X1 can be effectively corrected by retroviral mediated gene therapy and we have also seen success in a trial of gene therapy for ADA-SCID.

I have a particular interest in ADA-SCID, and one of my goals as Chair of the Working Party will be to gather information on how this condition is treated. Together with the previous Chairman, Jean-Laurent Casanova, we have already gathered information on the management practices of centres in Europe, and hope to put this together as a publication very soon. I am also keen to gather data on the outcome of BMT and PEG-ADA in patients with ADA-SCID as no formal outcome data on these treatments presently exist. I will be sending out questionnaires to you on this in the near future.



I believe very strongly in the ethos and spirit of ESID. I think the collaborative work of the Society has made enormous important scientific and clinical contributions to the understanding and management of primary immunodeficiencies. I hope that we can continue that collaborative endeavour over the coming years!

Bobby GASPAR

Focus on a country:

Established member Q&A
Srdjan Pasic
Pediatric Immunology
Mother and Child Health Institute
School of Medicine, University of Belgrade
Serbia and Montenegro

Can you give me some information about your background and can you tell me something about your career history?

My name is Srdjan Pasic, and I am consultant in pediatric immunology at the Mother and Child Health Institute, Belgrade, Serbia. In 1986, I completed medical training at the School of Medicine, University of Belgrade. During the next few years, I worked mainly at a busy pediatric intensive care unit. In 1990, I visited a pediatric ICU at the Children's Hospital, Pittsburgh, USA, where I learned more about intensive care of the patients who underwent organ transplantation.

How did you become interested in immunodeficiencies?

During my training in pediatrics, I worked together with dr Mario Abinun who suggested to me to join the department of pediatric immunology. This service, established by the late dr Mirko Mikuska in the early 70's, covered patients with PID, rheumatic diseases, infections and allergic diseases. I thought then — as I think now — that it should be the real scope of pediatric immunology. We investigated patients who were referred from the entire former Yugoslavia (app. 20 million), so I had plenty of opportunity to deal with patients affected with rare diseases. During the early 90's, I attended a course of immunology for clinicians at Hammersmith Hospital, London.

I also visited dr Gareth Morgan at GOS in London, where I got the general idea about diagnosis and follow-up of PID patients.

In the early 90's we performed the first haploidentical BMT's for SCID. Also, we followed a substantial number of patients with various PID. My special interest became the follow-up of CGD patients.

In 1995, I worked at the Newcastle-upon-Tyne BMT-unit for PID together with dr A.J. Cant and dr M. Abinun. It was a very useful clinical experience, and I established good contacts with my colleagues. After my return to Belgrade, we performed HLA identical BMT's for SCID, HLH and WAS.

What have been your achievements in research and patient care in the field of immunodeficiencies?

During the 90's, we recognized for the first time patients with Omenn syndrome. Later on, together with our Italian colleagues, we performed the first prenatal diagnosis in families affected with Omenn syndrome. I co-laborate very closely with prof. L.D. Notarangelo and his co-workers at Spedali Civili, Brescia, Italy. We are grateful to him because of his unselfish support. Also, I spent a splendid year at Brescia where I was really introduced in molecular diagnosis in PID. We did the molecular diagnosis in Serbian patients affected with Nijmegen breakage syndrome.

From the clinical point of view, I think that in the past few years we improved diagnostics, patient-care and prognosis of PID patients. Also, better recognition and treatment of patients with HLH is our achievement. Medical care of patients with agammaglobulinemia and CGD has also been improved in the past few years. Now, we are able to do BMT for PID and other inborn errors.

Serbia and Montenegro

Our future goals are introduction of our national registry of PID, as well as continuous medical education about PID for primary care physicians. I feel there is still a lot to do. We are trying to increase basic awareness of pediatricians about PID and to motivate them to carefully follow up these patients.

Research in PID is not possible in our country, due to limited funding and research grants. Another problem is the relative rarity of patients with certain PIDs. In my opinion, the best approach is to participate in international clinical and research studies in PID in our situation.

What kind of developments in immunodeficiency do you expect in the near future?

I was amazed to see the achievements of gene therapy for SCID and CGD. In spite of the current problems, I believe that gene therapy will offer a solution for definite treatment of certain PIDs. Also, I hope that in the near future selected patients who lack matched family or unrelated donors will be included in international trials/registers for gene therapy.

What is your advice for young people who want to launch their career in immunodeficiency?

The very first step would be to follow the right direction about the most important clinical or basic knowledge in PID. At this point an advice of senior colleagues may be crucial. The knowledge of common or unusual pediatric infectious diseases is the second important step. Also, one should be very curious and open-minded if one wants to become an expert in this field.

And - last but not least - what does ESID

mean to you?

Like someone once said: "this is my favourite meeting". Since EGID in 1992, Lugano, I missed only one ESID meeting. There, you can always meet good friends, discuss certain patients or initiate collaboration.

To end with, I would like to thank all the friends and lecturers from ESID for their friendly support!



Young Investigator Q&A
Gordana Petrovic
Pediatric Immunology
Mother and Child Health Institute
School of Medicine, University of Belgrade
Serbia and Montenegro

Can you tell me something about your career history?

My name is Gordana Petrovic, and I am specialist in pediatrics at the Mother and Child Health Institute, Serbia. I was born in small town, south Serbia. In 1997 I completed my medical studies. After I completed training in pediatrics in 2004 I have started master science degree studies in immunology at Medical School, University of Belgrade.

How did you become interested in immunodeficiencies?

During my training in pediatrics, I became interested in patients with immunodeficiencies and rheumatic disorders. I joined our pediatric immunology team and I hope I will gain both basic knowledge and clinical experience in approach to patients affected with PID.

What have been your achievements in patient care and/or immunodeficiency research up to now?

During this short period of time, I have followed patients affected with antibody deficiencies and chronic granulomatous disease. Our plans are to investigate the large cohort of patients affected with agammaglobulinemia and CVID, in order to evaluate the quality of life, complications, and long-term prognosis.

What do you hope to achieve in the future, and how are you planning to reach this goal?

I applied for the ESID Summer School 2005, where I expect to have an opportunity to learn more about recent advances in PID, as well as treatment and care of PID patients.

And - last but not least - what does ESID mean to you, and what would you want to change if you were president of ESID?

I do not know very much about ESID, simply because I had no opportunity so far to attend ESID meetings. I hope I will be able to attend the next meeting in Budapest. I visited the ESID website, where I got the impression that it is a very strong, world-wide network of clinicians and scientists involved in PID.



ESID Educational Working Party

€10 000 scholarship

The winner is : Tuba Turul from Ankara, Turkey,

who will work for one year in the laboratory of prof. Jacques van Dongen from Rotterdam, the Netherlands, on the effect of pre-BMT conditioning on reconstitution of B-cell and T-cell function after bone marrow transplantation in B-negative SCID patients. She will take this experience back to Ankara, with the idea of establishing better molecular diagnostics over there. She presented an excellent research protocol, as well as enthusiastic letters of support from Ilhan Tezcan and Fugen Ersoy from Turkey as well as from prof. van Dongen himself. The Educational Working Party expects Tuba, who participated in the ESID Summer School in Portugal in 2002, will make full use of her year of laboratory training in Rotterdam.

Later, you will read about her experiences in Rotterdam in upcoming issues of the ESID Newsletter.



ESID Educational Working Party



**ESID Summer School 2005
on Primary Immunodeficiencies
October 19 - 23, 2005
Mallorca, Spain**

Faculty: Anders Fath, Andrew Cant, Esther de Vries
Teresa Español, Georges Holländer,
Gavin Spickett, Jacques van Dongen

The course is geared toward young doctors in training
with a primary goal of education on the diagnosis, pathogenesis,
and treatment of primary immunodeficiencies.

For further information and application form
mail to Anders Fath, anders.fath@pediat.gu.se
Last day for application ~~May 30, 2005~~ now June 15 !!

Please, copy and advertise in your country's immunology societies,
and inform your young colleagues especially in the eastern European countries

Made Possible Through the Support of:

Baxter



octapharma

ZLB Behring
Biotherapies for Life

Extended deadline ESID Summer School - now June 15 !!



N.B. Deadline ~~May 30, 2005~~ now June 15 !!

**Application Form ESID Summer School 2005, Mallorca, Spain
October 19-23, 2005**

Please, print or type:

Last Name _____ Given Name _____ M.D. ___ Ph.D. ___ Other _____

Citizenship _____ Date of Birth _____ Sex M ___ F ___

Institution : _____

Address _____

Mailing Code _____ City _____ Country _____

Work Phone _____ FAX _____

E-mail (readable!) _____

Home Address _____

Mailing Code _____ City _____ Country _____

Home Phone _____ FAX _____

All communications will be via e-mail.

Please, enclose with the application:

1. Your curriculum vitae and a list of publications and/or meeting presentations.
2. A letter of support from your head of department or similar
3. Statement of career goals (typewritten about 500 words outlining your career goals and why attendance at the ESID Summer School in Primary Immune Deficiency Disorders will benefit you now and in the future.)
4. A case of primary immunodeficiency (or suspected PID)

Background:

- | | | |
|--|---------------------------------------|---|
| <input type="checkbox"/> Pediatrics | <input type="checkbox"/> Rheumatology | <input type="checkbox"/> Laboratory Immunology |
| <input type="checkbox"/> Internal Medicine | <input type="checkbox"/> Hematology | <input type="checkbox"/> Allergy/Immunology (adult) |
| <input type="checkbox"/> Clinical Immunology | <input type="checkbox"/> Other _____ | |

Selected applicants will be notified by August 10, 2005. They will receive free accommodation, but travel is at the expense of the applicant. A few travel grants will be available. Relevant information will be sent with the acceptance letter.

E-mail the completed form and attachment to "ESID Summer School" anders.fasth@pediat.gu.se. If problems alternatively send application to: Professor Anders Fasth, Dept of Pediatrics, Göteborg University, The Queen Silvia Children's Hospital, SE-41685 Göteborg, Sweden **not later than May 30, 2005. now June 15 !!**

MADE POSSIBLE THROUGH THE SUPPORT OF

Baxter



octapharma

ZLB Behring
Biotherapies for Life