



Mentors & friends -
young and old



Information - website,
newsletters, Facebook



Resources - for patients
and health professionals



Advocacy – national Ig
& Blood committees, SCIG,
newborn screening



Communication –
national conferences,
newsletters, face book,
birthday cards, picnics



Links – World PI Week,
IPOPI, Rare Disease Day



Empowerment –
encouraging members to
“share their story”



Strategies – Vision,
Mission, Goals, Values,
Fundraising



Australia

IDFA

Immune Deficiencies Foundation
www.idfa.org.au Australia


Major achievements since 2012:

- Increased membership
- New website
- Resource pack for patients
- Resources for health professionals
- 2 National Conferences
- Fundraising Gala Ball
- SCIG funding approved
- Volunteers and fundraising group
- Youth and young adult members group

VISION: A future where Primary Immune Deficiencies are diagnosed early, communities are more aware of the signs and symptoms of PID, and those affected by PID feel supported.

GOAL: Promote an understanding of PID within both the general and medical communities through: **Awareness** We work to increase PID awareness in the general and medical community. **Membership** We acknowledge that unity is strength and our aim is to reach and support all Australians with PID. **Advocacy** We will act for our members and their families.

Communication We will continue to develop and maintain our communication with members, their families, our partners stakeholders and key alliances.

 XIIIth Biennial Meeting Prague, Czech Republic 29 October - 1 November, 2014	About the poster presenters
	Christine Jeffery, Executive Officer IDFA
	Annette Farrugia, Board Director IDFA
	Parents of adult children with PID



Chloe, Annette, Christine & Adam

AUSTRIA

Austrian Support Group for Primary Immunodeficiencies





Key Goals of ÖSPID

- Support of patients and their families through contacts, meetings and the opportunity to exchange experiences.
- Information and training for members and their families.
- Cooperation with authorities, social security institutions, insurance companies and medical organizations.
- Educating the public about these diseases and degradation of ignorance and misunderstanding.
- Prevention of social exclusion.
- Suggestions and promotion of measures to improve medical education and early diagnosis.
- Help with legal issues.
- Help if problems with insurance.
- **Raise the Awareness for PID**



There are approximately 300 diagnosed Patients in Austria thereof 130 members at our group



 <p>XIIIth Biennial Meeting</p> <p>Prague, Czech Republic 29 October - 1 November, 2014</p>	Presenter	Nice to meet you!
	KARIN MODL	
	Founder & CEO (founded 2005)	
	Patient	

Belgium




Our Mission

- To get patients and their families out of their isolation, to guide them in their different steps and to provide answers to their main questions on PID;
- To represent patients with the public health authorities in order to raise awareness and to ensure better access to and reimbursement of health care in relation with PID;
- To foster international exchanges with a view to comparing existing therapies and propose new ones;
- To transmit relevant information to patients and their families, e.g. through a website and a newsletter.



Our Actions

- 2014 – Organisation of the 2nd National Family Day (20 April)
- 2013 – Organisation of the 1st National Family Day on PID (26 April)
- 2010 – Participation in the 3rd Day for Rare Diseases organised by RaDiOrg in Brussels
Sponsorised Horseback Hike to raise awareness of PID
- 2009 - Creation of BOPPI under the guidance of Dr FARBER
 - Participation in the IRIS conference on PID in Paris
 - Fundraising activities in collaboration with the National Opera and the Ferme Château Laneffe

 XIIIth Biennial Meeting <small>Prague, Czech Republic 29 October - 1 November, 2014</small>	About the poster presenter(s)	Nice to meet you!	
	<i>Edith Klapwijk – Chairperson</i>	 Edith	 Nathalie
	<i>Nathalie Thiébaud - Secretary</i>		
	<i>Edith has three children with DIP</i> <i>Nathalie is a DIP patient and has a son with DIP (and two without)</i>		

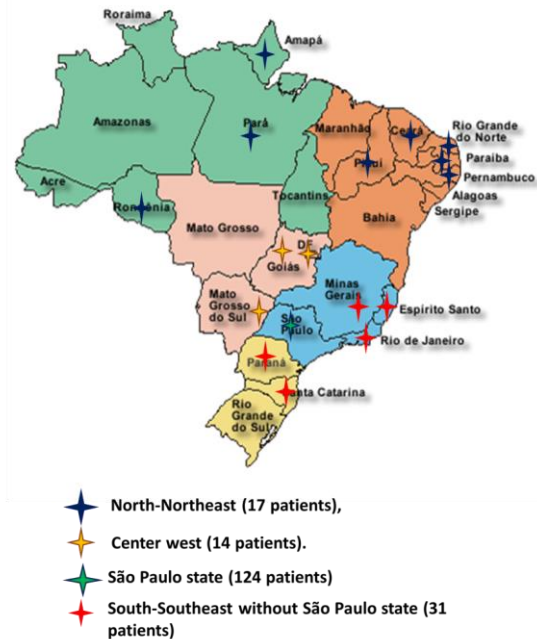
BRASIL?

- key goals or achievements?

Materials and Methods

We interviewed 186 patients and/or their carer distributed throughout Brazil between February 2012 and May 2013 using a printed and online questionnaire with 50 questions.

Fig. 1 – Distribution of patients by region





Results

Groups were compared and responses analyzed in order to verify regional differences and we found that over 98% of all patients have piped water and 93% have basic sanitary conditions. 74.5% have a computer, 47.8% have private insurance and most of these families (38.9%) survived on approx \$500 US/month.

We observed that many patients depend on public transportation, 57.8% don't have a car and 5.7% need 1 to 2 hours to reach the clinic for infusion or consultation. Approx 80% of the patients classified their health as poor before treatment but 81.4% classified their health as greatly improved following treatment.

Conclusions

Living conditions in Brazil are very similar among regions but we still have much room for improvement. This group of patients needs greater attention from the healthcare system in order to have a better quality of life.

 XIIIth Biennial Meeting Prague, Czech Republic 29 October - 1 November, 2014	About the poster presenter(s)	Nice to meet you!
	Lelia Bezzan	Please replace with picture of your NMO representative(s) attending the meeting 
	Regional Director Minas Gerais	
	Mother of Patient	

Canadian Immunodeficiencies Patient Organization

Our Vision

To provide advocacy, education and support for all immunodeficient patients diagnosed and not yet diagnosed in Canada

Our Mission

The Canadian Immunodeficiency Patient Organization is committed to improve the health and quality of life of all people with immunodeficiency and to ensure education of Physicians, Nurses and Patients.

Our Values

The Canadian Immunodeficiency Patient Organization is committed to the following values:

Inclusiveness | Connectedness
Advocacy | Excellence | Integrity
Respect | Collaboration

Our Goals

Care and Treatment

Achieve optimal comprehensive care for all people with Immunodeficiency.

Awareness

Raise awareness among people with Immunodeficiency, their immediate communities and health care providers.

Research

Promote research to improve treatment and ultimately to find a cure.

Education and Support

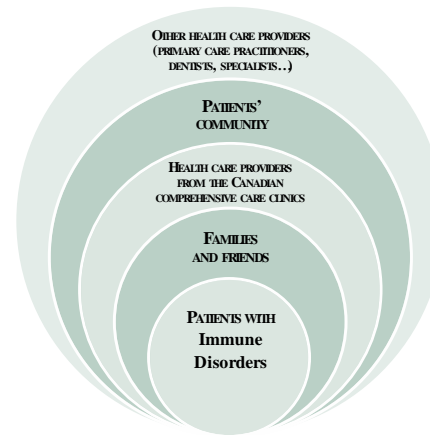
Provide effective delivery of information and support to patients and their families across Canada in both English and French.

Safe and Secure Supply

Advocate for access to a secure supply of the safest and most efficacious therapies for treatment of Immunodeficiencies.

Target Populations

The Canadian Immunodeficiency Patient Organization provides information, programs and services to.....



Our Global Responsibility

While the primary mission of the Canadian Immunodeficiency Patient Organization is to work within our own borders on behalf of Canadians, we recognize our responsibility to work with other global immunodeficiency groups to further its mission of TREATMENT FOR ALL.



Our Governance Priorities

A Cohesive Organization

Build a cohesive organization through a combination of strong, effective chapters with consistent collaboration between chapters and the national organization.

Increased Supporter Contact

Increase supporters in both the chapters and the national organization.

A Culture of Philanthropy

Develop a culture of philanthropy among the supporters of CIPO so as to be able to achieve the mission and goals of the organization.



Canadian Immunodeficiencies Patient Organization
Organisation Canadienne des personnes immunodéficientes



info@cipo.ca
www.cipo.ca



DENMARK

OUR INTERNAL ACTIVITIES

- **FAMILY SUMMER CAMP** yearly. Offering information on PID, exchange of experiences and opportunity for net-working.
- **FAMILY DAY TRIPS** in Jutland and on Zealand
- **YOUTH WEEKEND** in the spring time, giving the youth group the possibility to express their concerns and thoughts on various subjects concerning PID
- **INFORMATION DAY** for adult PID patients
- A webpage (www.idf.dk)
- A magazine IDF NYT (IDF NEWS) published 4x times yearly.



EXTERNAL ACTIVITIES

- Initiative to have SCID New born Screening included in the national health screening programme
- Joint project with other patient organisations campaigning to avoid PID patients included in "functional disorders"
- Cooperation between our NMO and the Nordic NMO's , Norway, Sweden, Finland and Iceland. Exchanging information and experiences within the Nordic countries.
- Member of RARE DISORDERS, DENMARK



XIIIth Biennial Meeting

Prague, Czech Republic
29 October - 1 November, 2014

About the poster presenter(s)

Lois Hibberd-Jorgensen, Sven Fandrup, Bo Austad and Jette Agerholm Olsen

*Board supporter , Board member, Vicepresident and member of IDF
All four are parents*

Nice to meet you!



FRANCE?

Our missions

- Support the families
- Improve early diagnosis and optimal treatments for PID
- Represent the patients
- Promote blood, plasma, bone marrow donation
- Support research



ASSOCIATION DE PATIENTS
DÉFICITS IMMUNITAIRES PRIMITIFS

Our achievements

- Two flats in Paris nearby Necker Hospital for parents having a child on a long term hospitalization
- Colloquium at the National Assembly - October 2014 : «Bubble Babies: towards neonatal screening of a fatal disease»
- A reliable website welcoming 4000 distinct visitors a month



**XIIIth Biennial
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About the poster presenter(s)

Ms ESTELLE POINTAUX



Chairperson



Patient organization

Nice to meet you







key goal: early diagnosis & appropriate therapy

actions & achievements 2013/2014

- appearance in nationwide TV shows
- awareness campaigns in print and online media
 - > award from „Marion und Bernd Wegener Stiftung“
- 11 CME events all over Germany
- digital posters all over Berlin for Day of Immunology
- new flyer „guideline for PID diagnostics“
- new mascot „purple bacteria“
- film version of dsai-comic (in progress)
- relaunch of new dsai website



 XIIIth Biennial Meeting Prague, Czech Republic 29 October - 1 November, 2014	About the poster presenter(s)		Nice to meet you!		
	Gabriele Gründl – Chairwoman – founder		  		
	Birgit Brandl - employee				
	Andrea Neuner - employee				

INDIA



WPIW 2014: Silent March At New Delhi.




WPIW 2013 :International CME at KIMS, Bhubaneswar, Odisha



International CME at KIMS, Bhubaneswar, Odisha



CME at Apollo Hospital, Bhubaneswar, Odisha

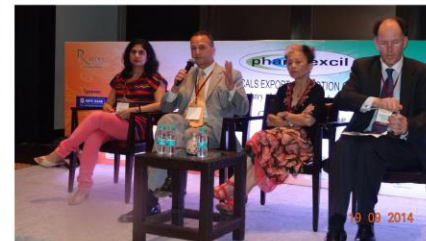
 XIIIth Biennial Meeting <small>Program, Council, Resolutions</small> <small>28th October - 1st November, 2014</small>	About the Poster Presenter(s)
	RUBBY CHAWLA / RAKESH CHAWLA
	FOUNDER & PRESIDENT / CO-FOUNDER & EXECUTIVE MEMBER
	PARENTS



Presentation & Stall at PIDCON 2014, BHU, Varanasi, U.P



IAPO South-east Asia Regional Meeting at Delhi



Govt. Initiatives on Rare Diseases and Orphan Drugs at Hyderabad



IPSPI Presentation & Stall at International Conference, Mumbai



Health and Family Welfare Minister Dr. Harshvardhan
Govt. of India, New Delhi

MALAYSIA



Goals of Malaysia Patient Organisation for Primary Immunodeficiencies (MyPOPI):

- To raise awareness of PI in Malaysia.
- To improve diagnosis & access to early diagnosis for PID patients in Malaysia.
- To serve as a communication bridge to make known the difficulties faced by PID patients & addressing the issues faced by them.

NMO representatives attending IPOPI Biennial Meeting 2014

Professor Dr Lokman Mohd Nor,
Professor, Division of Clinical Immunology, Dept. of Paediatrics, UKM Medical Center, KL

Dr Adli Ali, Clinical Lecturer & Paediatrician, UKM Medical Center, KL

Bruce Lim, MyPOPI President

Karen Koh, MyPOPI Vice President

Key Achievements

27 Oct 2013: First PID patient workshop held in Kuala Lumpur.

24 Jan 2014: Interim organisation of MyPOPI formed.




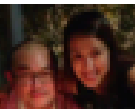
15 Aug 2014: Official registration of MyPOPI as a society.

WPIW kicked off in Malaysia with:

•2 live TV interviews with HCP & patient's family

•3 live radio interviews with HCP & patient's family

•4-page spread on PID & MyPOPI in Malaysia's leading daily (3.3 million readership)

 XIIIth Biennial Meeting <small>Prague, Czech Republic 29 October - 1 November, 2014</small>	About the poster presenter(s)	Nice to meet you!
	Karen Koh	  
	Vice President and Parent of PID Patient	
	Connection to the PID Community: Parent	
	Prof. Lokman	Dr. Adli
		Bruce & Karen



PID Patient Events

- National PID Patient and Family Conference
- 25th Anniversary of IDFNZ
- Regional Patient meetings
- Christmas Parties for PID Patients

Zoe (DiGeorge / BMT + Thymus)

Rare Disease Day



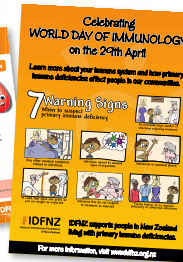
Manawa (CGD / BMT)



Education and Awareness

- PI Awareness week
- Poster displays, GP and hospital talks
- Literature and information widely distributed
- Advertising editorials promoting PID warning signs
- Sponsorship for clinician CME e.g. ASCIA, IPIC, ESID
- SCID new born testing lobbying
- "Investigate Immunity" school education series
- Rare Disease Day picnic and balloon release

PI Week



Luka (SCID / BMT)



Hannah (CID / BMT)



Ashton (SCID / BMT)

Ongoing PID Family Support

- Family linking events
- Respite Care Programme - 4 holiday homes for respite and recuperation
- Patient Centre Project
- Free pamper holidays - Waiheke Island
- ALL4GOOD giving back programme

Individual PID Patient Support

- SCIG pumps provided free
- Free Adrenaline Injectors
- Advocacy and Information
- Family assistance grants and vouchers
- Hospital support for families undergoing BMT
- Grants for overseas treatment e.g. Thymus Transplant
- Family linking



Iziyah (CGD / BMT)



About the poster presenter(s)

Vicki Tattley

Chairman IDFNZ, New Zealand NMO representative

Parent of 20 yr old Aidan, long-serving Board member IDFNZ

Nice to meet you!



Portugal



ASSOCIAÇÃO PORTUGUESA
DE DOENTES COM
IMUNODEFICIÊNCIAS
PRIMÁRIAS



APDIP - The Portuguese Association of Primary Immunodeficiencies

History and Goals

Has started in 2002 in Oporto. In 2010 with the election of a new Board APDIP is infused with new a dynamic approach, making all efforts to better understand who the Portuguese patient are and what are their needs.

APDIP is constituted solely of volunteers who endeavor to work with health officials, institutions, physicians, families and patients to improve the general conditions to Portuguese Patients.

PID awareness is key for quicker diagnosis and better access to care and the Portuguese PID Patient group main concern.

APDIP organize, every year, the Meeting of Families with PID. Patients, their families, physicians and nurses took part in the meeting sharing their experiences and expertise.

Congress Presenters



Maria João Mousinho
President
Living with PI

I was diagnosed at 35 years old, when my daughter was born. Since that moment, I was always very sick. But my story is also the story of my twin sister. She had 7 years without diagnosis. She was only diagnosed when I started to have the same symptoms. Since we do the treatment of immunoglobulin we started to have a normal life again.



Ricardo Pereira
Treasurer
Living with PI

Hey, my name is Ricardo and I'm a eclectic person, very passionate about life. I born with X-Linked Agammaglobulinemia. Many people ask me what limitations do I have! I answer always with a smile. Smiles also lead to happiness and a good health so I try to live my life in that way.



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About the poster presenters

Maria João Mousinho, Ricardo Pereira

President, Treasurer

Patient, Patient



facebook



website



twitter

ROMANIA

GOALS:

- to support all patients with PIDs from Romania (adults and children) in order to achieve their fundamental rights regarding medical healthcare, social assistance and their education.
- to fight for an earlier access to diagnose a PID
- to acquire the proper treatment for all patients with PIDs
- to organize meetings with doctors, medical staff, media and politicians for a better understanding of PIDs



ACHIEVEMENTS 2014:

- first patients meeting in Targu Mures (24-27.04.2014)
- third celebration of PIDs week - in Timisoara
- first camp for Romanian children with PIDs in June at Raul Sadului, near Sibiu (24 children with their parents reached the camp)
- six new booklets ready for distribution to doctors, patients in schools, media
- ARPID became a member of Rare Diseases Organization in Romania
- attendance to medical conferences, meetings with media and politicians



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ROMANIA

BÂLDEA ARTEMIZA

CHAIRMAN OF ARPID

PATIENT



Republic of Serbia

POSPID is an NGO advocating for access of PID patients to early diagnose, safe treatment, proper medical care and regular health insurance.



<http://pospid.org.rs>



Main achievements in last two years??

Continually raising awareness on PID using different media, events, congresses, festivals, art performances & promotions (Expose!)

Providing support to referral hospitals, PIDs, lab, microscope, education, support in fitting with authorities

Dealing with patient's health issues by **advocating to authorities,**
organizing needed help

Collaborating in region meetings, skype conferences, calls

Providing psycho/social support to patients:

summer camps, meetings, workshops, phone calls

Establishing and Running

National Organization for Rare Diseases:

First National Conference on RD

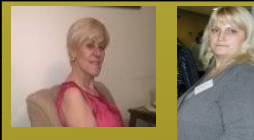
About the poster presenter(s)

Dragana Koruga
Snezana Obradovic

Dragana is Chairing the POsPID – The NMO from Serbia – Snezana is representing the POsPID Assembly

Connection to the PID Community: Parents

Nice to meet you!



Dragana?

Snezana?





AEDIP

Asociación Española de Déficits Inmunitarios Primarios

You can follow us on



WWW.FACEBOOK.COM/AEDIP.ASL

@AEDIP_ASL

WWW.AEDIP.COM

ACTIVITIES 2013/2014

A two days weekend for families and patients was held in Burgos with the participation of 50 people. Different lectures and sessions with psychologist and physio-therapist were very much appreciated.

-Both years (2013 and 2014) during the WPIW the General assembly and a lecture for AEDIP members, were celebrated, in Madrid and Sevilla.

-In Sevilla a One-day meeting for pediatricians and different professionals on Diagnosis and therapy for PID was attended by 60 participants, before the General Assembly

AEDIP was present at the 2014 SEI Meeting (Spanish Society for Immunology) and to the SEICAP Meeting (Spanish Society for Pediatric Allergy and Clinical Immunology)

The President has had meetings with several pharmaceutical companies to improve the budget for publications.

And we receive consultations through the Forum at the web site and also by telephone; many letters to improve the patient's care have been send to hospitals and general doctors.



The Spanish association for patients with PID (AEDIP) was created in 1990 with the collaboration of physicians and patients from the three main centres working, at that time, with PID patients: Barcelona, Madrid and Palma de Mallorca.

AEDIP is an IPOPI member since the beginning and one member of the Board participates at the biennial IPOPI meeting, during the ESID Congress meeting.

There are more than 100 members (patients and relatives) and many "followers" of the web site and Forum. The nº of pages visited last year was more than 350.000 and the Forum receives many consultations about diagnosis and therapies

We have an Annual assembly with a "get together" to facilitate contacts between participants.

We will include several pictures of our activities

All IPOPI booklets, in Spanish, have been introduced in the web and there are also different papers on diagnosis and therapy of PID's, as well as links with other organisations.

NMO's play an important role in the quality of life of patients with PID's



About the poster presenter(s)

DRA. TERESA ESPAÑOL BUEREN

MEDICAL ADVISER

FOUNDER AND MEDICAL ADVICE

Nice to meet you!





XIIIth Biennial Meeting

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SWEDEN



Every person with a PI and their families should have the possibility to live a good life

About PIO

- Established 1978
- 1000 members
- 6 regional groups

PIO offers

- Education, information
- Booklets/leaflets
- Counselling, support
- Members magazine
- Family camps
- Member meetings
- Internet forum
- Website: www.pio.nu
- Staffed office



Key goals

- Early and correct diagnosis – incl. newborn screening
- Access to adequate, individualized treatment

Activities

- Awareness campaigns incl. World PI week
- Meetings with key persons
- Lectures
- Lobby work

PIO supports

- The National Quality Register - PIDcare
- National guidelines for diagnosis and treatment



Anneli Larsson
Executive Director, PIO

Carmilla Ottoson
PIO member

Lotta Billquist
Vice Chair, PIO

Stefan Nordeman
Chair, PIO

Linda Zakrisson
Board member, PIO

Axel Jakobsson
PIO member

Maria Michelfelder
Finance Manager, PIO



Good knowledge about your disease for better quality of life

Thai Patient Organization for Primary Immunodeficiency



History



October 2013

The inception of ThaiPOPI was born from the first meeting in Thailand between IPOPI and Asia Pacific Association of Pediatric Allergy, Respiriology and Immunology (APAPARI 2013)



MAY 2014

ThaiPOPI was formed by the spirit of unity and hope from the diversified groups : PID community, doctors, nurses, medical personnel and volunteers

Key goals

To promote the knowledge and understanding of primary immunodeficiency to Thai general public and the medical society.

To provide the PID patients access to early diagnostic care and treatments.

To establish network among PID patients, family members and healthcare providers.

Strategic plan

1. Increase PID awareness in the general and medical community.
2. Strengthen and expand the PID network.
3. Advocate for better collaboration between government and PID patients
4. Fund raising to support PID patients and ThaiPOPI's activities.



Achievement

1. Working committee meeting to strategize goals and action plans.



2. Knowledge sharing through different PR channels and activities.

3. Attend Thailand Allergists' Annual Meeting October 4, 2014 to publicize ThaiPOPI and network to recruit more members.



Brochure

Address : ThaiPOPI Department of Allergy & Immunology, Pediatrics dept Faculty of Medicine Chulalongkorn University, 1873 Rama 4 Road, Pathumwan Bangkok 10330, Thailand



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Hi! My name is Dr.Dara Mairiang and I am honored to be an advisor to ThaiPOPI.

Sawasdee! My name is Jirutchaya Khanta besides a Chairperson of ThaiPOPI, I am a proud mother of two lovely PID patients ages 4 and 2 years.



LINE
ID: ThaiPOPI



The Netherlands

Re-print brochures and new brochures



new website



Stichting voor Afweerstoornissen

-Established in 1985

- 295 members (= 316 patients)
(About 1700 patient in the Netherlands)

-Two meetings a year (April / November)
also for young patients

- Involvement in research projects






Young adult weekend Ardennes



Awareness campaign

Altijdziek.nl



 XIIIth Biennial Meeting Prague, Czech Republic 29 October - 1 November, 2014	About the poster presenter(s)	Nice to meet you!	
	Petra Vera Chair		
	Kees Waas Secretary		
	Both are parents from IPID patients		

TURKIYE



IMMUN YETMEZLİK DERNEĞİ

Association of Turkish Patients with Immune Deficiency

?

115 members

?

747 patients & families

?

768 nurses & doctors

?

?

• Balloon launch at PI week

• Awareness meetings for physicians

• General assembly of IMYED

?

?

?

A miracle has happened

Gene therapy cured
WAS patient



XIIIth Biennial Meeting

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About the poster presenter(s)

Selcan Kaya

Chairperson of IMYED

Patient

Nice to meet you!

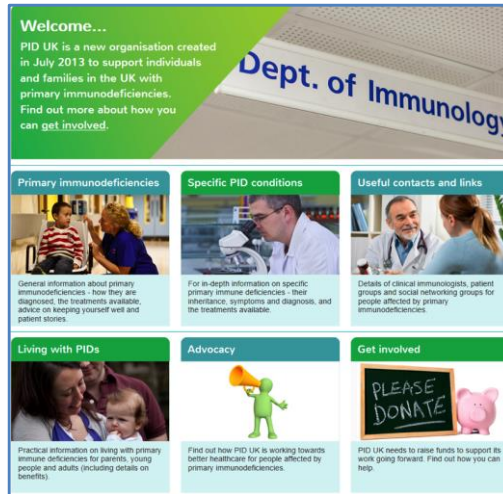


United Kingdom

Launched July 2013: www.piduk.org



Involvement in campaigns



Information and support

- Responding to medical, benefits, insurance and rights queries
- Condition information sheets
- Advice leaflets




Updating members on health, community & research news

Raising awareness

Patient stories in national & local press



Newsroom, newsletters, monthly e-bulletins

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	Dr Susan Walsh and Suzanne Fox Directors of PID UK (SW) and member of Patient Representative Panel (SF)	 Susan  Suzanne
	Suzanne Parent	

United States



Founded in 1980, the Immune Deficiency Foundation is the national patient organization in the United States dedicated to improving the diagnosis, treatment and quality of life of persons with primary immunodeficiency diseases through advocacy, education and research.

www.primaryimmune.org



IDF REACH

33,000 visits on average per month to IDF websites




32,000+ people receive the *IDF Advocate* newsletter three times a year

19,000 people receive IDF's monthly E-Newsletters

13,000 patients and healthcare professionals attended more than **180** educational presentations in **134** cities (37 states) in 2013

150,000 educational materials distributed in 2013

30 Staff Members and **thousands** of volunteer hours

	About the poster presenters	Nice to meet you!
XIIIth Biennial Meeting <small>Prague, Czech Republic 29 October - 1 November 2014</small>	Marcia Boyle & John Seymour, PhD, LMFT	 
	<small>Roles in the IMiD: Marcia Boyle – IDF President & Founder, John Seymour, PhD, LMFT – Chair IDF Board of Trustees</small>	
	<small>Marcia's Connection to the PID Community: Parent John's Connection to the PID Community: Parent & Spouse</small>	

...

