Pitfalls in the organization of an APS multicentre study: Lessons from the "Euro-Phospholipid", the "CAPS Registry" and the PRECISESADS project

Ricard Cervera
Department of Autoimmune Diseases
Hospital Clínic
Barcelona

CLÍNIC BARCELONA Hospital Universitari

Lupus anticoagulant

~~Lupus anticoagulant~~

~~Lupus anticoagulant~~

Positive serological tests for syphilis

~~Lupus anticoagulant~~

~~Positive serological tests for syphilis~~

~~Lupus anticoagulant~~

~~Positive serological tests for syphilis~~

Anti-cardiolipin antibodies

~~Lupus anticoagulant~~

~~Positive serological tests for syphilis~~

~~Anti-cardiolipin antibodies~~

~~Lupus anticoagulant~~

~~Positive serological tests for syphilis~~

~~Anti-cardiolipin antibodies~~

APS without aPL

~~Lupus anticoagulant~~

~~Positive serological tests for syphilis~~

~~Anti-cardiolipin antibodies~~

~~APS without aPL~~

~~Lupus anticoagulant~~

~~Positive serological tests for syphilis~~

~~Anti-cardiolipin antibodies~~

~~APS without aPL~~

Thrombosis marker

~~Lupus anticoagulant~~

~~Positive serological tests for syphilis~~

~~Anti-cardiolipin antibodies~~

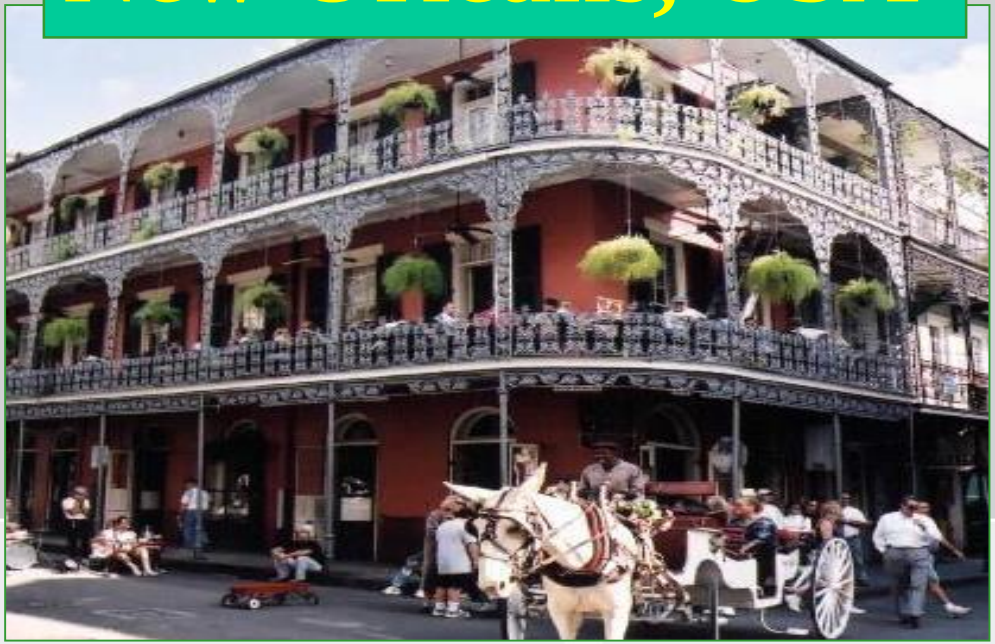
~~APS without aPL~~

~~Thrombosis marker~~

European Forum on aPL

New Orleans, USA

1996



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European Forum on aPL

New Orleans, USA

1996

PROMOTERS:
Marie-Claire Boffa
Jean-Charles Piette
(Paris, France)

Paris

1997

PROMOTERS:
Marie-Claire Boffa
Jean-Charles Piette
(Paris, France)

1st Meeting of the European Forum on aPL

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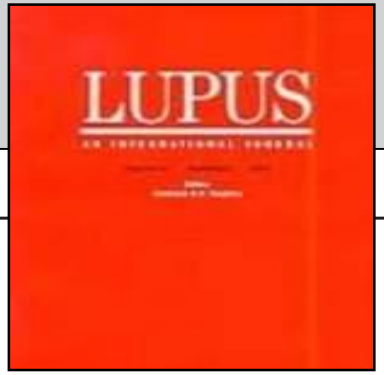
Hospital Universitari



Lupus (2009) 00, 1–6
http://lup.sagepub.com

EDITORIAL

European Working Party on Systemic Lupus Erythematosus and European Forum on antiphospholipid antibodies: two networks promoting European research on autoimmunity

R Cervera, MD, PhD, FRCP[1] and A Tincani[2]
[1]Department of Autoimmune Diseases, Institut Clínic de Medicina i Dermatologia (ICMiD), Hospital Clínic, Barcelona, Catalonia, Spain; and
[2]Rheumatology and Clinical Immunology, Spedali Civili e Università di Brescia, Brescia, Italy

EUROPEAN FORUM ON ANTIPHOSPHOLIPID ANTIBODIES

OBJECTIVES

- **1.** To move forward in standardization workshops
- **2.** To initiate new biological,clinical and therapeutical projects
- **3.** To find a consensus on controversial issues

Web contents: EFAPL Info Desk.
Last updated: 23 April 1999

EUROPEAN FORUM ON ANTIPHOSPHOLIPID ANTIBODIES

GENERAL COORDINATOR

Marie-Claire Boffa
Paris, France

1997-2004

Angela Tincani
Brescia, Italy

2004-2009

CLÍNIC BARCELONA Hospital Universitari

EUROPEAN FORUM ON ANTIPHOSPHOLIPID ANTIBODIES

GENERAL COORDINATOR

Ricard Cervera
Barcelona, Catalonia

2009-2017

Denis Wahl
Nancy, France

2017- now

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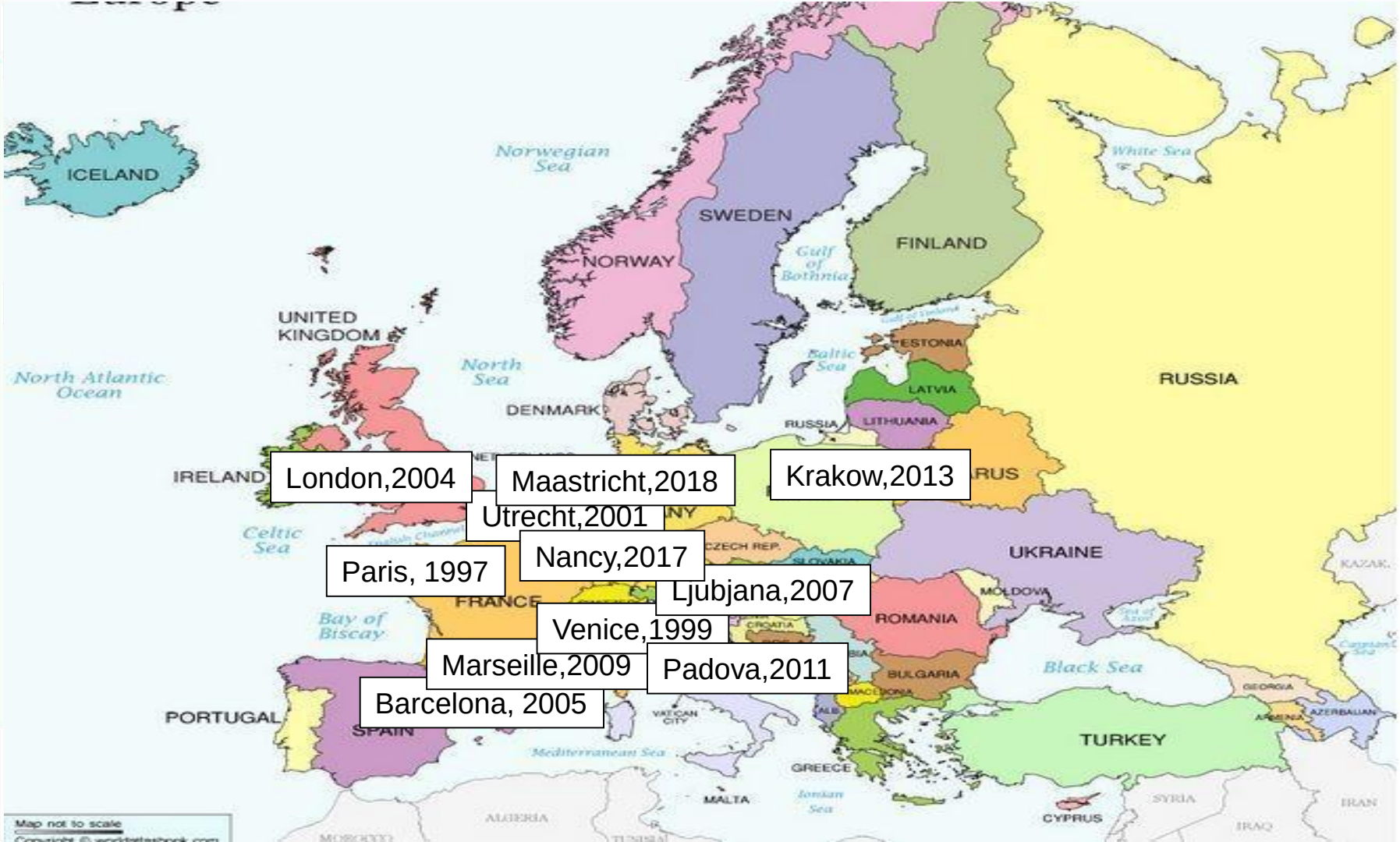
ICELAND
Norwegian Sea
SWEDEN
FINLAND
White Sea
NORWAY
Gulf of Bothnia
UNITED KINGDOM
North Atlantic Ocean
North Sea
Baltic Sea
ESTONIA
LATVIA
RUSSIA
DENMARK
RUSSIA
LITHUANIA
IRELAND
London,2004
Maastricht,2018
Krakow,2013
Utrecht,2001
Celtic Sea
Paris, 1997
Nancy,2017
UKRAINE
Ljubjana,2007
FRANCE
MOLDOVA
Bay of Biscay
Venice,1999
ROMANIA
Marseille,2009
Padova,2011
BULGARIA
Black Sea
Barcelona, 2005
PORTUGAL
SPAIN
VATICAN CITY
TURKEY
Mediterranean Sea
GREECE
MALTA
Ionian Sea
CYPRUS
Map not to scale

Euro-Phospholipid on Line

Official Web-site of the "European Forum on Antiphospholipid Antibodies"

MULTICENTRE STUDIES

- Euro-Phospholipid project
- The CAPS Registry
- APLS Babies Register
- Familial Antiphospholipid Syndrome
- Warfarin in the Antiphospholipid Syndrome (WAPS)
- Pulmonary Hypertension and Antiphospholipid Antibodies
- Standardization of the Antiphospholipid Antibodies
- Cerebral Ischaemia in the Primary Antiphospholipid Syndrome: Source of Thrombi European Study (STEP)
- FcgRIIa polymorphism in the Antiphospholipid Syndrome
- CRP and ischemic cerebral manifestations

- New kit according to the Forum proposals
- Quantitative LA tests
- β-2-GPI specific LAC assay
- Factors that influence the anti-β-2-GPI ELISA
- Avidity of anti-β-2-GPI antibodies
- Binding of β-2-GPI to phospholipids
- Standardization of ELISA anti-PE antibodies
- Soluble CD40 ligand in APS
- TACT and TACIT Projects
- aPL tissue targeting
- FcγRIIA in SLE, APS and CAPS
- Genetics of APS: FcγRIIA polymorphisms and beyond
- Annexin V in APS
- APS in women presenting with recurrent miscarriage
- PedAPS Registry
- European Registry of Obstetric Antiphospholipid Syndrome

Euro-Phospholipid on Line

Official Web-site of the "European Forum on Antiphospholipid Antibodies"

MULTICENTRE STUDIES

- Registry of infants with thrombosis born to mothers having aPL
- Brain neurosonography in infants born to mothers having aPL
- ALIWAPAS trial
- Infections and aPL
- Atherosclerosis in APS
- Multiple positivity of aPL
- Future projects

EXTENDED REPORT

Validation of the preliminary criteria for the classification of catastrophic antiphospholipid syndrome

R Cervera, J Font, J A Gómez-Puerta, G Espinosa, M Cucho, S Bucciarelli, M Ramos-Casals, M Ingelmo, J-C Piette, Y Shoenfeld, R A Asherson for the Catastrophic Antiphospholipid Syndrome Registry Project Group*

Ann Rheum Dis 2005;64:1205–1209. doi: 10.1136/ard.2004.025759

EXTENDED REPORT

Catastrophic antiphospholipid syndrome during pregnancy and puerperium: maternal and fetal characteristics of 15 cases

UNLOCKED

This paper is freely available online under the BMJ Journals unlocked scheme, see http://ard.bmj.com/info/unlocked.dtl

José A Gómez-Puerta, Ricard Cervera, Gerard Espinosa, Ronald A Asherson, Mario Garcia-Carrasco, Izeias P da Costa, Danieli C O Andrade, Eduardo F Barba, Alexander Makatsaria, Silvia Bucciarelli, Manuel Ramos-Casals, Josep Font, for the Catastrophic Antiphospholipid Syndrome Registry Project Group/European Forum on Antiphospholipid Antibodies*

Ann Rheum Dis 2007;66:740–746. doi: 10.1136/ard.2006.061671

Lupus (2003) 12, 530–534
www.lupus-journal.com

Catastrophic antiphospholipid syndrome: international consensus statement on classification criteria and treatment guidelines

RA Asherson[1], R Cervera[2]*, RG de Groot[3], D Erkan[4], M-C Boffa[5], J-C Piette[6], MA Khamashta[6] and Y Shoenfeld[7]
for the Catastrophic Antiphospholipid Syndrome Registry Project Group†
[1]Rheumatic Diseases Unit, University of Cape Town, Groote Schuur Hospital, Cape Town, South Africa; [2]Department of Autoimmune Diseases, Institut Clinic d'Infeccions i Immunologia, Hospital Clinic, Barcelona, Catalonia, Spain; [3]Department of Rheumatology, University Medical Center Utrecht, Utrecht, The Netherlands; [4]Hospital for Special Surgery, Weill Medical College of Cornell University, New York, USA; [5]Department of Internal Medicine, Hôpital Pitié-Salpêtrière, Paris, France; [6]Lupus Unit, The Royal Institute, St. Thomas' Hospital, London, UK; [7]Center for Autoimmune Diseases, Chaim Sheba Medical Center, Tel-Hashomer, Israel

EXTENDED REPORT

Thrombotic microangiopathic haemolytic anaemia and antiphospholipid antibodies

G Espinosa, S Bucciarelli, R Cervera, M Lozano, J-C Reverter, G de la Red, V Gil, M Ingelmo, J Font, R A Asherson

Ann Rheum Dis 2004;63:730–736. doi: 10.1136/ard.2003.007245

EXTENDED REPORT

Long term outcome of catastrophic antiphospholipid syndrome survivors

D Erkan, R A Asherson, G Espinosa, R Cervera, J Font, J-C Piette, M D Lockshin for the Catastrophic Antiphospholipid Syndrome Registry Project Group

Ann Rheum Dis 2003;62:530–533

Intestinal Involvement Secondary to the Antiphospholipid Syndrome (APS): Clinical and Immunologic Characteristics of 97 Patients: Comparison of Classic and Catastrophic APS[1]

Ricard Cervera, MD, PhD, FRCP,* Gerard Espinosa, MD, PhD,* Aida Cordero, MD,* M. Rosa Oltra, MD,* Ainhoa Unzurrunzaga, MD,* Tomeu Rossinol, MD,* Joan Plaza, MD,* Silvia Bucciarelli, MD, PhD,* Manuel Ramos-Casals, MD, PhD,* Miguel Ingelmo, MD, PhD,* Ronald A. Asherson, MD, PhD, FRCP,† Josep Font, MD, PhD, FRCP,*,‡ and for the Catastrophic Antiphospholipid Syndrome (CAPS) Registry Project Group

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Vol. 80, No. 6
Printed in U.S.A.

Catastrophic Antiphospholipid Syndrome

Clues to the Pathogenesis from a Series of 80 Patients

RONALD A. ASHERSON, RICARD CERVERA, JEAN-CHARLES PIETTE, YEHUDA SHOENFELD, GERARD ESPINOSA, MICHELLE A. PETRI, EUGENE LIM, TANG CHING LAU, ANAGHA GURJAL, ANNA JEDRYKA-GÓRAL, HANNA CHWALINSKA-SADOWSKA, ROBIN J. DIBNER, JORGE ROJAS-RODRÍGUEZ, MARIO GARCIA-CARRASCO, JOHN T. GRANDONE, ANN L. PARKE, PAULO BARBOSA, CARLOS VASCONCELOS, MANUEL RAMOS-CASALS, JOSEP FONT, AND MIGUEL INGELMO

CONCISE REPORT

Disseminated intravascular coagulation in catastrophic antiphospholipid syndrome: clinical and haematological characteristics of 23 patients

R A Asherson, G Espinosa, R Cervera, J A Gómez-Puerta, J Musuruana, S Bucciarelli, M Ramos-Casals, A L Martínez-González, M Ingelmo, J C Reverter, J Font, D A Triplett, for the Catastrophic Antiphospholipid Syndrome Registry Project Group*

Ann Rheum Dis 2005;64:943–946. doi: 10.1136/ard.2004.026377

Clin Rheumatol (2007) 26:2109–2114
DOI 10.1007/s10067-007-0634-x

ORIGINAL ARTICLE

The role of malignancies in patients with catastrophic anti-phospholipid (Asherson's) syndrome

W. Miesbach · R. A. Asherson · R. Cervera · Y. Shoenfeld · J. Gomez Puerta · G. Espinosa · S. Bucciarelli · Members of the CAPS Registry Group

EXTENDED REPORT

The acute respiratory distress syndrome in catastrophic antiphospholipid syndrome: analysis of a series of 47 patients

S Bucciarelli, G Espinosa, R A Asherson, R Cervera, G Claver, J A Gómez-Puerta, M Ramos-Casals, M Ingelmo, J Font for the Catastrophic Antiphospholipid Syndrome Registry Project Group*

Ann Rheum Dis 2006;65:81–86. doi: 10.1136/ard.2005.037671

Vol. 54, No. ●, Month 2006, pp 000–000
DOI 10.1002/art.●
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Mortality in the Catastrophic Antiphospholipid Syndrome

Causes of Death and Prognostic Factors in a Series of 250 Patients

Silvia Bucciarelli,[1] Gerard Espinosa,[1] Ricard Cervera,[1] Doruk Erkan,[2] José A. Gómez-Puerta,[1] Manuel Ramos-Casals,[1] Josep Font,[1] and Ronald A. Asherson[3] for the CAPS Registry Project Group (the European Forum on Antiphospholipid Antibodies)

The Clinical Spectrum of Catastrophic Antiphospholipid Syndrome in the Absence and Presence of Lupus

ULAS D. BAYRAKTAR, DORUK ERKAN, SILVIA BUCCIARELLI, GERARD ESPINOSA, and RONALD ASHERSON, for the Catastrophic Antiphospholipid Syndrome Project Group

(J Rheumatol 2007;34:346–52)

Hospital Universitari

Euro-Phospholipid on Line

Official Web-site of the "European Forum on Antiphospholipid Antibodies"

MULTICENTRE STUDIES

- Euro-Phospholipid project
- The CAPS Registry
- APLS Babies Register
- Familial Antiphospholipid Syndrome
- Warfarin in the Antiphospholipid Syndrome (WAPS)
- Pulmonary Hypertension and Antiphospholipid Antibodies
- Standardization of the Antiphospholipid Antibodies
- Cerebral Ischaemia in the Primary Antiphospholipid Syndrome: Source of Thrombi European Study (STEP)
- FcgRIIa polymorphism in the Antiphospholipid Syndrome
- CRP and ischemic cerebral manifestations

1997

"EURO-PHOSPHOLIPID" PROJECT

Coordinators:

Ricard Cervera, Josep Font (Barcelona)*,

Jean-Charles Piette, Marie-Claire Boffa (Paris),

Munther A. Khamashta and Graham R.V. Hughes (London)

*deceased

CLÍNIC BARCELONA Hospital Universitari

TWIN PROJECTS

“EURO-LUPUS” PROJECT:
Morbidity and mortality in 1,000 European SLE patients during a 10-year follow-up period

20th Century

European Working Party on SLE

21th Century

“EURO-PHOSPHOLIPID” PROJECT:
Morbidity and mortality in 1,000 European APS patients during a 10-year follow-up period

European Forum on aPL

CLÍNIC BARCELONA Hospital Universitari

“EURO-PHOSPHOLIPID” PROJECT

AIM:

To evaluate prospectively the clinical and serological manifestations and the long-term evolution of the APS in Europe by means of a 10-year-follow-up study of 1000 patients attending 20 university centres

“EURO-PHOSPHOLIPID” PROJECT

- **PART I: Cross-sectional Study (2000)**
  - Epidemiological features
  - Clinical and immunological patterns
- **PART II: 5-yr follow-up study (2005)**
  - Assessment of morbidity and mortality
  - Risk factors with prognostic value
- **PART III: 10-yr follow-up study (2010)**
  - Assessment of morbidity and mortality after a long-term follow-up period

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“EURO-PHOSPHOLIPID” PROJECT
Participating Centres (I)

- Hospital Clínic, Barcelona, Catalonia, Spain
- Hospital Clínico, Málaga, Spain
- Hospital Regional del SAS, Málaga, Spain
- St.Thomas´Hospital, London, England, UK
- Chaim Sheba Medical Center,Tel-Hashomer,Israel
- CHU Pitié-Salpetrière, Paris, France
- CHRU de Nîmes, Nîmes, France
- Hôpital Claude Huriez, Lille, France
- Hvidovre Hospital, Hvidovre, Denmark
- Univ. Medical School, Debrecen, Hungary

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“EURO-PHOSPHOLIPID” PROJECT
Participating Centres (II)

- Spedali Civili, Brescia, Italy
- Policlinico Le Scotte, Siena, Italy
- Università di Pisa, Pisa, Italy
- IRCCS Policlinico, Milano, Italy
- Hippocration Hospital, Athens, Greece
- University Hospital, Utrecht, The Netherlands
- Medical University, Sofia, Bulgaria
- Cliniques Univer. Saint-Luc, Brussels, Belgium
- Hospital S. António, Porto, Portugal
- Technische Univer Dresden, Dresden, Germany
- Rheumaklinik Berlin-Buch, Berlin, Germany

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European Forum on aPL

"EURO-PHOSPHOLIPID" PROJECT

ARTHRITIS & RHEUMATISM
Vol. 46, No. 4, April 2002, pp 1019–1027
DOI 10.1002/art.10187
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2002

Antiphospholipid Syndrome

Clinical and Immunologic Manifestations and Patterns of Disease Expression in a Cohort of 1,000 Patients

Ricard Cervera,[1] Jean-Charles Piette,[2] Josep Font,[1] Munth
Yehuda Shoenfeld,[4] María Teresa Camps,[5] Soren Jacobsen,[6] Gabrie
Irene Kontopoulou-Griva,[9] Mauro Galeazzi,[10] Pier Lu
Ronald H. W. M. Derksen,[12] Philip G. de Groot,[12] Erika Gromni
Marta Mosca,[15] Stefano Bombardieri,[15] Frédéric Houssiau,[16] J
Isabelle Quéré,[17] Eric Hachulla,[18] Carlos Vasconcelos,[1
Antonio Fernández-Nebro,[21] Marie-Claire Boffa,[2] Graham
Miguel Ingelmo,[1] for the Euro-Phospholipid Proje

2009

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Extended report

Morbidity and mortality in the antiphospholipid syndrome during a 5-year period: a multicentre prospective study of 1000 patients

R Cervera,[1] M A Khamashta,[2] Y Shoenfeld,[3] M T Camps,[4] S Jacobsen,[5] E Kiss,[6]
M M Zeher,[6] A Tincani,[7] I Kontopoulou-Griva,[8] M Galeazzi,[9] F Bellisai,[9] P L Meroni,[10]
R H W M Derksen,[11] P G de Groot,[12] E Gromnica-Ihle,[13] M Baleva,[14] M Mosca,[15]
S Bombardieri,[15] F Houssiau,[16] J-C Gris,[17] I Quéré,[17] E Hachulla,[18] C Vasconcelos,[19]
A Fernández-Nebro,[21] J-C Piette,[22] G Espinosa,[1] S Bucciarelli,[1] C N Pisoni,[2]
M L Bertolaccini,[2] M-C Boffa,[22] G R V Hughes,[2] on behalf of the Euro-Phospholipid
Project Group (European Forum on Antiphospholipid Antibodies)

2014

rst, published on January 24, 2014 as 10.1136/annrheumdis-2013-204838

Clinical and epidemiological research

EXTENDED REPORT

Morbidity and mortality in the antiphospholipid syndrome during a 10-year period: a multicentre prospective study of 1000 patients

R Cervera,[1] R Serrano,[1] G J Pons-Estel,[1] L Ceberio-Hualde,[2] Y Shoenfeld,[3]
E de Ramón,[4] V Buonaiuto,[4] S Jacobsen,[5] M M Zeher,[6] T Tarr,[6] A Tincani,[7]
M Taglietti,[7] G Theodossiades,[8] E Nomikou,[8] M Galeazzi,[9] F Bellisai,[9] P L Meroni,[10]
R H W M Derksen,[11] P G D de Groot,[12] M Baleva,[13] M Mosca,[14] S Bombardieri,[14]
F Houssiau,[15] J-C Gris,[16] I Quéré,[16] E Hachulla,[17] C Vasconcelos,[18]
A Fernández-Nebro,[19] M Haro,[19] Z Amoura,[20] M Miyara,[20] M Tektonidou,[21]
G Espinosa,[1] M L Bertolaccini,[2] M A Khamashta,[2] on behalf of the Euro-Phospholipid
Project Group (European Forum on Antiphospholipid Antibodies)

CLÍNIC BARCELONA
Hospital Universitari

“CAPS REGISTRY”
(European-Extended Project)

Coordinators:

Ricard Cervera, Ronald A. Asherson*,

Gerard Espinosa (Barcelona),

Doruk Erkan (New York),

Yehuda Shoenfeld (Tel-Hashomer)

*deceased

CLÍNIC BARCELONA Hospital Universitari

“CAPS REGISTRY”

AIM:

To put together all the published case reports as well as the newly diagnosed cases of catastrophic APS from all over the world in a web-site based registry in order to increase our knowledge of this “rare” disease.

CLÍNIC BARCELONA Hospital Universitari

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THE "CAPS" REGISTRY

REGISTRY OF THE "EUROPEAN FORUM ON ANTIPHOSPHOLIPID ANTIBODIES" FOR PATIENTS WITH THE "CATASTROPHIC" ANTIPHOSPHOLIPID SYNDROME

COORDINATORS

Ricard Cervera, Jean Charles Piette, Yehuda Shoenfeld, Josep Font, and Ronald A. Asherson on behalf of the European Forum on Antiphospholipid Antibodies.

AIM

To establish an International Registry of all diagnosed patients with the "catastrophic" antiphospholipid syndrome, considered as a "rare disease".

For additional information and inclusion of patients, please e-mail: cervera@medicina.ub.es

For review of the already collected data, please click: CAPS registry

Internet

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Table 1. General clinical manifestations of patients with catastrophic APS.

PATIENT No.	SEX	AGE*	DIAGNOSIS	PREVIOUS APS MANIFESTATIONS	PRECIPITATING FACTOR
1	F	32		Subclavian vein thrombosis, fetal losses, thrombocytopenia, skin ulcers	Post-fetal loss
2	M	43	Lupus-like		
3	F	22	Lupus- like		
4	F	22	SLE		
5	M	40	PAPS	Myocardial infarction, epilepsy	

Listo Internet

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Table 2. Thrombotic clinical manifestations of patients at the time of catastrophic APS.

N.	PERIPHERAL	CEREBRAL	CARDIAC	PULMONARY	INTRABDOMINAL	SKIN	OTHER	TREATMENT	OUTCOME
1	Subclavian	Infarcts	Failure		Renal		Retinal artery	Ancrod, cyclo	Recov
2	DVT	Infarcts		ARDS	Renal	LR, ulcers		S, P, cyclo, AC	Recov
3		Infarcts		ARDS	Renal	LR, necrosis	Retinal artery	S, P, cyclo, AC	Recov
4			MI, VL	Microthrombi	Renal, hepatic, pancreatic	Digital ischemia		S, cyclo	Death
5		Infarcts	MI, VL		Renal	LR		S, AC	Death
6			MI	ARDS	Renal, adrenal, gastrointestinal		Myometrium		Death
7		Infarcts			Hepatic, renal, mesenteric			S, P, AC, cyclo	Recov
8		Infarcts	MI		Renal	LR, ulcers	Mononeuritis	S	Death
9					Hepatic, renal, portal vein	LR		S, P, HD	Recov
10					Hepatic, renal, adrenal			S, AC	Recov

Listo Internet

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Customize Search Sign in My Yahoo! Health Yahoo! Yahoo! Mail

Table 3. Laboratory findings of patients with catastrophic APS.

No	PLATELET COUNT	HEMOLYSIS	DIC	SCHISTOCYTE	IgG-aCL	IgM - aCL	LA	ANA	DNA	ENA
1	Normal	-	-	-	NR	NR	+	1:320	+	NR
2	Low	-	-	-	+	+	+	1:320	-	Ro
3	Low	-	-	-	+	+	+	1:120	-	Ro, La, RNP
4	Low	-	-	-	High +	-	NR	1:640	+	NR
5	Low	-	-	-	High +	-	+	-	-	NR
6	Low	+	+	+	+	-	NR	+	+	-
7	Normal	-	-	-	High +	NR	+	1:80	NR	-
8	Normal	-	-	-	High +	Moderate +	+	+	+	-

Listo Internet

Archivo Edición Ver Favoritos Herramientas Ayuda
Atrás Adelante Detener Actualizar Inicio Búsqueda Favoritos Historial Correo Imprimir Modificar
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Customize Search Sign in My Yahoo! Health Yahoo! Yahoo! Mail

145. Jacek Musial, M.D.Professor of Medicine, Jagiellonian University School of Medicine, Skawińska 8, 31-066 Krakow, Poland. Tel. and fax: (+48-12) 430-53-14, Fax:(+48-12) 430-52-03; E-mail: mmmusia@kinga.cyf-kr.edu.pl

146. Bernardino Roca, MD. Department of Internal Medicine, Hospital General de Castelló, Av. de Benicàssim, s/n, 12004-Castelló, Spain. Phone: 34.964.211000 (Ext. 1531, 1313); Fax: 34.964.252345; e-mail: brocav@terra.es

147. Hiroyuki Okura, Miyo Tomon, Shoji Nishiyama, Tadashi Yoshikawa.Patent foramen ovale and "catastrophic" antiphospholipid syndrome. Intern med 39(1): 83,2000.

148. Mandal B, Rathore S, Douglas AF. Catastrophic antiphosphoplipid syndrome presenting as dilated cardiomyophathy with bilateral branch retinal artery thrombosis. Int J Clin Pract 54(8): 550-551, 2000.

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150. Ricard Cervera, MD. Department of Autoinmune Diseases, Hospital Clínic, Villarroel, 170. 08036- Barcelona, Catalonia, Spain. Phone/Fax: 34.93.227.57.74; e-mail: RCERVERA @clinic.ub.es

151-152-153. Maria Tektonidou, Haralampos M. Moutsopoulos, Department of Pathophysiology, Medical School, National University of Athens, 75 Mikras Asias st. 114 27 Athens, Greece. Phone: 30.10.7771163; Fax: 30 10 7462664; e-mail: balts@otenet.gr

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EUROPEAN FORUM ON
ANTIPHOSPHOLIPID ANTIBODIES

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CAPS REGISTRY

REGISTRY OF THE "EUROPEAN FORUM ON ANTIPHOSPHOLIPID ANTIBODIES" FOR PATIENTS WITH THE "CATASTROPHIC" ANTIPHOSPHOLIPID SYNDROME

COORDINATORS

Ricard Cervera, Gerard Espinosa, Doruk Erkan, and Yehuda Shoenfeld on behalf of the European Forum on Antiphospholipid Antibodies.

AIM

To establish an International Registry of all diagnosed patients with the "catastrophic" antiphospholipid syndrome, considered as a "rare disease".

For additional information and inclusion of patients, please e-mail: rcervera@clinic.ub.es

For review of the already collected data, please go to: Public CAPS Registry

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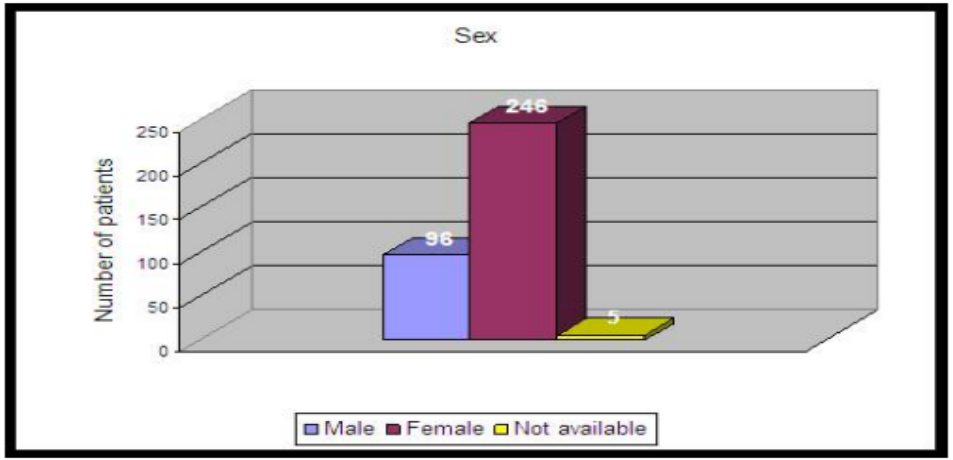

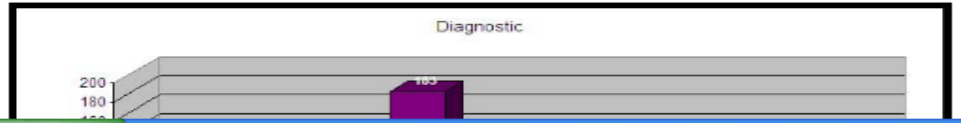

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1998

Catastrophic Antiphospholipid Syndrome

Clinical and Laboratory Features of 50 Patients

RONALD A. ASHERSON, RICARD CERVERA, JEAN-CHARLES PIETTE, JOSEP FONT, J. T. LIE*, ARSINUR BURCOGLU, KEN LIM, FRANCISCO J. MUÑOZ-RODRÍGUEZ, ROGER A. LEVY, FRANÇOIS BOUÉ, JÉRÔME ROSSERT, AND MIGUEL INGELMO

2001

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Catastrophic Antiphospholipid Syndrome

Clues to the Pathogenesis from a Series of 80 Patients

RONALD A. ASHERSON, RICARD CERVERA, JEAN-CHARLES PIETTE, YEHUDA SHOENFELD, GERARD ESPINOSA, MICHELLE A. PETRI, EUGENE LIM, TANG CHING LAU, ANAGHA GURJAL, ANNA JEDRYKA-GÓRAL, HANNA CHWALINSKA-SADOWSKA, ROBIN J. DIBNER, JORGE ROJAS-RODRÍGUEZ, MARIO GARCÍA-CARRASCO, JOHN T. GRANDONE, ANN L. PARKE, PAULO BARBOSA, CARLOS VASCONCELOS, MANUEL RAMOS-CASALS, JOSEP FONT, AND MIGUEL INGELMO

2009

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Catastrophic antiphospholipid syndrome (CAPS): Descriptive analysis of a series of 280 patients from the "CAPS Registry"

Ricard Cervera [a,*], Silvia Bucciarelli [a], Miguel A. Plasín [a], José A. Gómez-Puerta [a], Joan Plaza [a], Guillermo Pons-Estel [a], Yehuda Shoenfeld [b], Miguel Ingelmo [a], Gerard Espinos [a], for the Catastrophic Antiphospholipid Syndrome (CAPS) Registry Project Group (European Foru on Antiphospholipid Antibodies) [c]

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[b] Department of Medicine 'B' and Center for Autoimmune Diseases, Chaim Sheba Medical Center, Tel Aviv University, Tel Hashomer, Israel
[c] See complete list of members of the CAPS Registry at the end of the article

2016

Autoimmunity Reviews xxx (2016) xxx–xxx

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Review

Catastrophic antiphospholipid syndrome (CAPS): Descriptive analysis of 500 patients from the International CAPS Registry

gnasi Rodríguez-Pinto [a], Marta Moutinho [a], Irene Santacreu [a], Yehuda Shoenfeld [b], Doruk Erkan [c], Gerard Espinosa [a], Ricard Cervera [a,*], the CAPS Registry Project Group (European Forum on Antiphospholipid Antibodies) [1]:

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[b] Zabludowicz Center for Autoimmune Diseases, Sheba Medical Center, Tel Aviv, Israel
[c] Barbara Volcker Center for Women and Rheumatic Disease, Hospital for Special Surgery, New York, NY, United States

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Asherson RA, *et al. Medicine (Baltimore)*. 2001;80:355-77.
Cervera R, *et al. J Autoimmun*. 2009;32:240-5.
Rodriguez-Pinto I, *et al. Autoimmun Rev*. 2016;15:1120-4.

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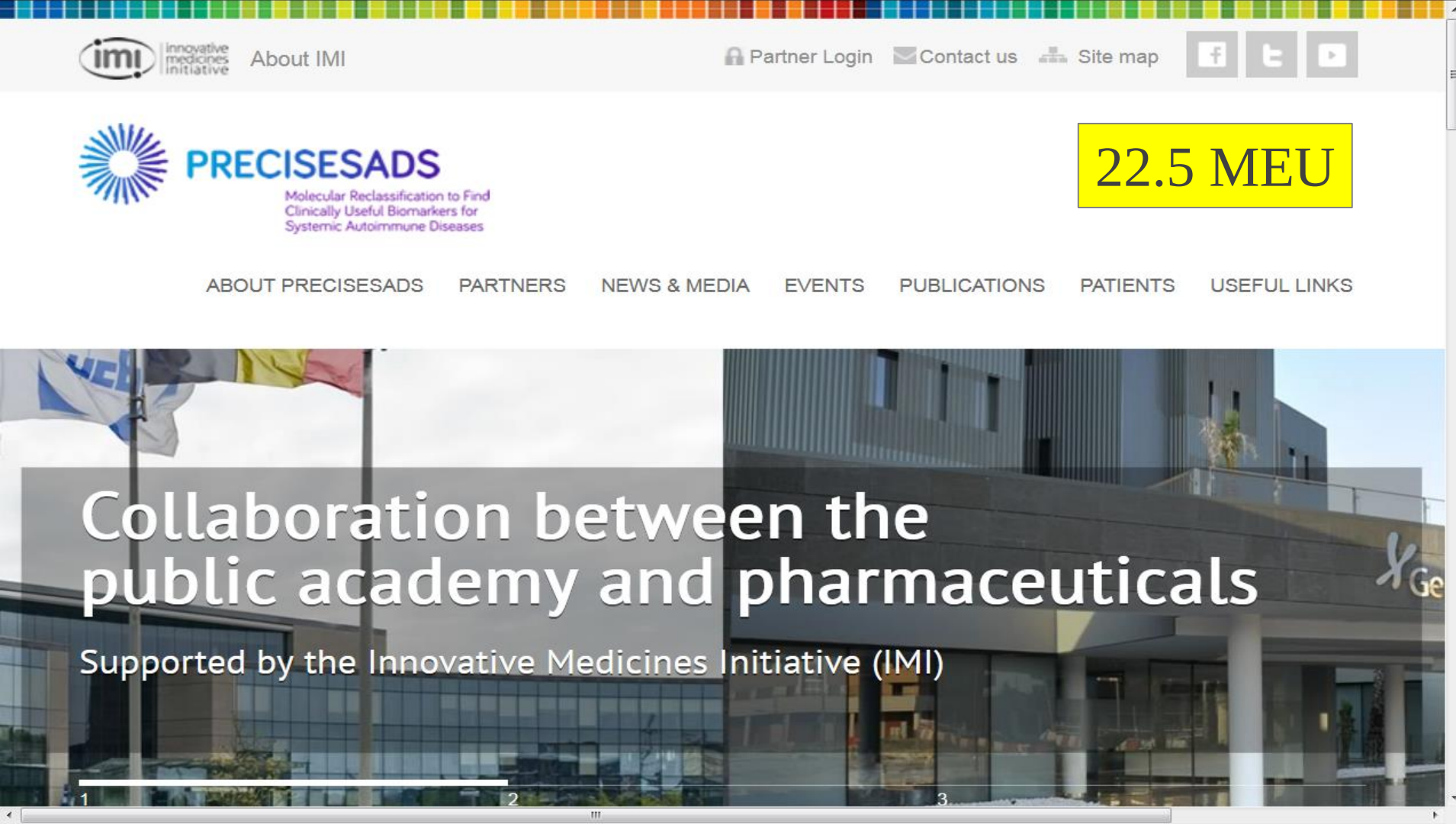
Hospital Universitari

Molecular reclassification to find clinically useful biomarkers for systemic autoinmune diseases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Supported by the Innovative Medicines Initiative (IMI)
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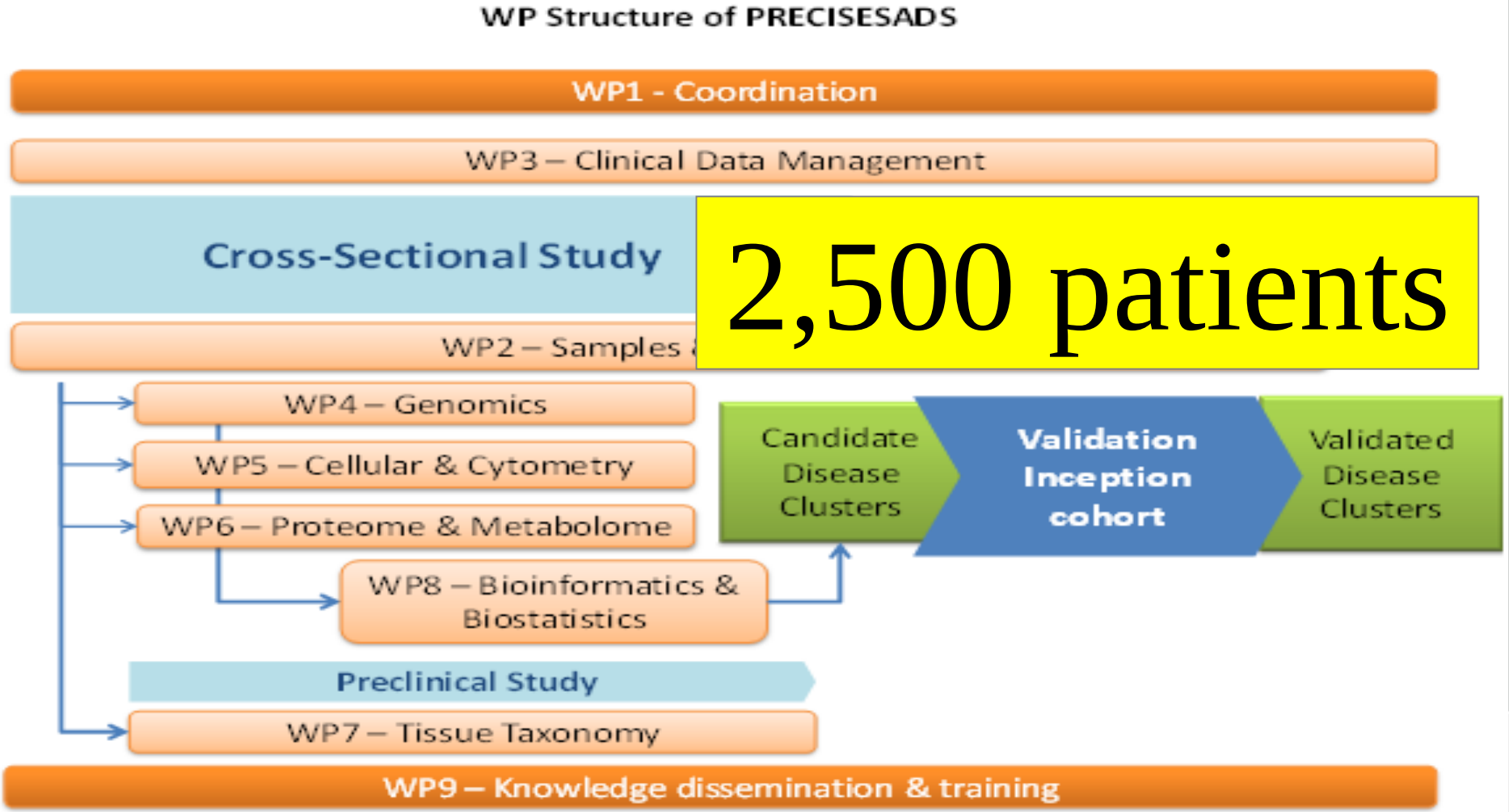
Expected Impact

By means of state-of-the-art high-throughput technologies and the application of integrative bioinformatics strategies we expect to yield major impacts at multiple levels.

The following outcomes will directly result from the activity of the PRECISESADS consortium:

- Identification of biomarkers for clinical use (diagnosis, prognosis, response to drugs) for SAD patients.
- Identification of clusters of biomarkers that characterize groups of SADs patients.
- Reclassification of SADs based on meaningful clinical biomarkers.
- Crucial scientific insights on the interplay between different clinical features among SADs.
- Development of a protocol for patient management.


WP Structure of PRECISESADS
WP1 - Coordination
WP3 – Clinical Data Management
Cross-Sectional Study
2,500 patients
WP2 – Samples
WP4 – Genomics
WP5 – Cellular & Cytometry
WP6 – Proteome & Metabolome
WP8 – Bioinformatics & Biostatistics
Candidate Disease Clusters
Validation Inception cohort
Validated Disease Clusters
Preclinical Study
WP7 – Tissue Taxonomy
WP9 – Knowledge dissemination & training

European Forum on Antiphospholipid Antibodies