

APS ACTION NEWS (2010-2015)

APS ACTION Convenes the 6th Annual Summit

November 2015 – The 6th Annual APS ACTION Summit took place on November 6th, 2015 in San Francisco, California, USA. Presenters were Drs. Danieli Andrade, Doruk Erkan, Guilherme Ramires de Jesus, Guillermo Pons-Estel, Savino Sciascia, Ozan Unlu, and Stephane Zuily.

APS ACTION Presents at the American College of Rheumatology (ACR) 2015 Annual Scientific Meeting

November 2015 – Based on the analysis of the APS ACTION Clinical Database, three abstracts were presented during the 2015 ACR Scientific Annual Meeting that was held in San Francisco, CA on November 6-11, 2015: a) Cluster Analysis for Identification of Different Clinical Phenotypes Among Antiphospholipid Antibody-Positive Female Patients (Presenter: Dr. Stephane Zuily); b) Determinants of Thrombosis in Patients Presenting with Obstetric APS (Presenter: Dr. Guilherme Ramires de Jesus); and c) Prospective follow-up Analysis for One-Year First and Recurrent Thrombosis Risk (Presenter: Dr Doruk Erkan). In addition, Dr Maria Laura Bertolaccini presented the data on APS ACTION Core Laboratory Validation Exercise - Comparison of Enzyme-Linked Immunosorbant Assay (ELISA) and Chemiluminescence Immunoassay (CIA).

APS ACTION Presents at the International Society on Thrombosis and Haemostasis (ISTH) 2015 Annual Scientific Meeting

June 2015 – Based on the APS ACTION Core Laboratory Validation Exercise, two abstracts were presented during the ISTH annual meeting held in Toronto, Canada on June 20-25, 2015: a) An International performance assessment of lupus anticoagulant test using standardised methods and reagents (Presenter: Dr Ian Mackie); and b) Comparison of Enzyme-Linked Immunosorbant Assay (ELISA) and Chemiluminescence Immunoassay (CIA) (Presenter: Dr. Maria Laura Bertolaccini).

APS ACTION Holds 5th Annual Working Meeting

June 2015 – The 5th Annual APS ACTION Working Meeting took place on June 10th, 2015 in Rome, Italy. Sessions included the Executive Committee report by Doruk Erkan and Danieli Andrade, Core Laboratory Validation Exercise discussions moderated by Maria Laura Bertolaccini and Hannah Cohen, and group discussions on the future APS ACTION studies.

APS ACTION Presents at the European League Against Rheumatism (EULAR) Annual Meeting 2015

June 2015 - Based on the analysis of the APS ACTION Clinical Database an abstract was presented during the 2015 EULAR Annual Meeting that was held in Rome, Italy on June 10—13, 2015: Cluster Analysis for Identification of Different Clinical Phenotypes among Antiphospholipid Antibody-Positive Patients (Presenter Dr. Stephane Zuily).

APS ACTION Executive Committee Announces the New Co-Chair

February 2015 – The Executive Committee of APS ACTION selected Danieli Andrade (University of Sao Paulo, Sao Paulo, Brazil) to co-chair the committee together with Dr. Doruk Erkan. .

APS APS ACTION Convenes the 5th Annual Summit

November 2014 – The 5th Annual APS ACTION Summit took place on November 14, 2014 in Boston, MA, USA .

APS ACTION Holds 4th Annual Working Meeting

June 2014 – The 4th Annual APS ACTION Working Meeting took place on June 11th, 2014 in Paris, France. Sessions included the Executive Committee report by Doruk Erkan, Research Update by Doruk Erkan, Core Laboratory Validation Exercise Update by Maria Laura Bertolaccini, Hannah Cohen, and Vittorio Pengo, and group discussions on the ongoing and future clinical research studies.

APS ACTION is a Proud Sponsor of World Thrombosis Day

April 2014 – [World Thrombosis Day](#) is October 13, 2014 and APS ACTION is a proud sponsor. The first ever World Thrombosis Day is led by the International Society on Thrombosis and Haemostasis (ISTH) in an effort to increase awareness of thrombosis as a top cardiovascular killer globally.

APS ACTION Selects the 4th Honorary Member

October 2013 – APS ACTION appointed Takao Koike, MD from the Hokkaido University, Japan as the 4th Honorary Member. Honorary Members comprise a small, highly selective group of individuals who have made major contributions to the field of APS and/or have demonstrated extraordinary service to APS ACTION.

APS ACTION Presents at the American College of Rheumatology Annual Meeting

October 2013 – Three APS ACTION-related presentations were given during the 2013 American College of Rheumatology Scientific Annual Meeting that was held in San Diego, CA on November October 26-30, 2013: a) Antibodies in Diagnosis and Follow-up of Rheumatic Disease Study Group presentation by Doruk Erkan, MD (APS ACTION Executive Committee Chair); b) Oral Concurrent Session “The Association Between Antiphospholipid Antibodies and Related Clinical Outcomes: A Critical Review Of The Literature” by Cecilia Chighizola, MD (APS ACTION Steering Committee Member); and c) Clinical Posters Exhibit “APS ACTION: Three Year Update” presentation by JoAnn Vega, CCRC (APS ACTION Lead Coordinator).

APS ACTION Convenes the 4th Annual Summit

September 2013 – The 4th Annual APS ACTION Summit took place on September 16-17, 2013 in Rio de Janeiro, Brazil

APS ACTION Presents at the 14th International Congress on Antiphospholipid Antibodies

September 2013 – An update on the APS ACTION Clinical Studies was presented at the 14th International Congress on Antiphospholipid Antibodies (September 18-21, Rio de Janeiro), which was chaired by one of the APS ACTION Executive Committee Members Dr Roger Levy. Of note, APS ACTION Executive Committee Chair Dr Doruk Erkan will be the organizer of the 15th International Congress on Antiphospholipid Antibodies, which will take place in Istanbul, Turkey in September 2016 (www.apsistanbul2016.org).

APS ACTION Condolence Notice

August 2013 – *It is with deep sorrow and much sympathy that we note the passing of our valued colleague and friend, Dr. Silvia Pierangeli. Dr. Pierangeli was always a strong advocate and leader for APS. She was a true inspiration to us all. Her enthusiasm and collaborative energy helped drive APS and APS ACTION to where it is today. She will be missed.*

APS ACTION Promotes Selected Members to the Steering Committee

July 2013 – APS ACTION promoted Danieli Oliveira de Andrade, MD, Alessandra Banzato, PhD, Cecilia B. Chighizola, MD, Guilherme de Jesus, MD, Guillermo Ruiz-Irastorza, MD, Maria Tektonidou, MD, and Zhuoli Zhang, MD to the Steering Committee.

APS ACTION Young Scholars Publish the First Study Designed and Conducted by APS ACTION.

July 2013 – The APS ACTION Young Scholars, Laura Andreoli, Alessandra Banzanto, Cecilia Chighizola, Guillermo Pons-Estel and Guilherme de Jesus along with Doruk Erkan, published a report on the estimated frequency of antiphospholipid antibodies in general population patients with pregnancy morbidity, stroke, myocardial infarction and deep vein thrombosis (Arthritis Care Res (Hoboken). 2013 Jul 16. doi: 10.1002/acr.22066. [Epub ahead of print]).

APS ACTION Reaches Another Registry Milestone

July 2013 – As of July 31, 2013, APS ACTION has enrolled over 220 patients in its International Clinical Database and Repository. Currently, 19 centers are participating in the study.

APS ACTION Article in the APS Foundation of America, Inc Newsletter

July 2013 – APS ACTION has two major clinical research projects now open for recruitment– the “Registry” and “HCQ Study.” As of April 2013, 16 centers have received IRB approval to participate in the “Registry” and 7 centers been approved to participate in the “HCQ Study.” [Read More](#)

APS ACTION Holds 3rd Annual Working Meeting

June 2013 – The 3rd Annual APS ACTION Working Meeting took place on June 12, 2013 in Madrid, Spain. Sessions included the Executive Committee report by Doruk Erkan, Core Laboratory Validation Exercise Update by Silvia Pierangeli and Vittorio Pengo, and a group discussion on the ongoing clinical and Young Scholar projects.

APS ACTION Presents at the New York State Rheumatology Society Annual Meeting

May 2013 – The Executive Committee Chair Doruk Erkan, MD was invited to the Annual New York Rheumatology Society Meeting to give an update on APS ACTION and ongoing research.

APS ACTION Lead Coordinator JoAnn Vega was selected as HSS Employee of the Month for May 2013

May 2013 – Congratulations to JoAnn Vega for being selected Employee of the Month for May 2013. JoAnn manages multiple lupus and antiphospholipid syndrome clinical research projects and has been a member of the HSS family since March 2005. As APS ACTION Lead Coordinator, JoAnn monitors more than 15 international centers on a daily basis. She contributes greatly to the success of her division and performs above and beyond what is required.

APS ACTION is now on Twitter

April 2013 – Please follow us on Twitter [@APS_ACTION](#)

APS ACTION Reaches Registry Milestone

March 2013 – As of March 15, 2013, APS ACTION has enrolled over 100 patients in its International Clinical Database and Repository. Currently, 16 centers are participating in the study.

APS ACTION Recruits First Patient from Greece for the Hydroxychloroquine Trial

February 2013 – Congratulations to Maria Tektonidou of the University of Athens for recruiting the first patient for the Hydroxychloroquine (HCQ) Trial in February 2013. APS ACTION is actively recruiting patients for the trial now

that seven centers have received institutional review board approval. The purpose of the HCQ trial is to determine whether HCQ is beneficial in reducing blood clot formation in patients with positive aPL.

APS ACTION Creates Scientific Advisory Subcommittee

January 2013 – The Executive Committee created a new Scientific Advisory Subcommittee that will be chaired by Phillip de Groot. The new subcommittee will evaluate all future research proposals with the help of external/internal reviewers as needed. The Subcommittee's final recommendations will be submitted to the Executive Committee.

APS ACTION Selects Honorary Members

January 2013 – APS ACTION appointed Graham Hughes, MD, Nigel Harris, MD and Sam Machin, MD as Honorary Members. Honorary Members comprise a small, highly selective group of individuals who have made major contributions to the field of APS and/or have demonstrated extraordinary service to APS ACTION.

APS ACTION Reaches Laboratory Agreements

January 2013 – Laboratory partnership agreements were signed with the Instrumentation Laboratory and INOVA Diagnostics for APS ACTION Core Laboratories.

APS ACTION Presents at the American College of Rheumatology Annual Meeting

November 2012 – Two APS ACTION-related presentations were given during the 2012 American College of Rheumatology Scientific Annual Meeting that was held in Washington, D.C., on November 9-14, 2012: 1) Antiphospholipid Syndrome Study Group presentation by Doruk Erkan, MD (APS ACTION Executive Committee Chair) about the accomplishments of the network; and 2) Clinical Posters Exhibit presentation by JoAnn Vega, CCRC (APS ACTION Lead Coordinator).

APS ACTION Convenes 3rd Annual Summit

November 2012 – The 3rd Annual APS ACTION Summit took place on November 8-9, 2012 in Washington, D.C., USA. Members discussed the progress of the main APS ACTION research projects and listened to presentations on the "Young Scholar aPL Prevalance project" by Cecilia Chighizola and the "Core Laboratories Validation" project by Silvia Pierangeli and Vittorio Pengo.

APS ACTION Re-Elects Executive Chair

November 2012 – The Chair of the Executive Chair, Doruk Erkan, was re-elected based on the Executive Committee's nomination and voting during the 3rd Annual Summit. Dr. Erkan will serve as the Executive Chair for the period of January 1, 2013 to January 1, 2015.

APS ACTION Receives IND Approval for the Hydroxychloroquine Trial

November 2012 – The IND application for the Hydroxychloroquine Trial was approved by the Food and Drug Administration on November 6, 2012 under section 505(i) of the Federal Food, Drug and Cosmetic Act.

APS ACTION Receives New York Community Trust (NYCT) Grant

October 2012 – The New York Community Trust awarded APS ACTION \$70,000 per year for three years for the Hydroxychloroquine Trial.

APS ACTION Establishes DSMB Board for Hydroxychloroquine Trial

August 2012 – The Data and Safety Monitoring Board (DSMB) for the Hydroxychloroquine Trial includes Robert Roubey, MD (chair), Steven Levine, MD, Steven Krilis, PhD, Jacob Rand, MD and Jordan Jaskwhich Elm, PhD (external). Members of the DSMB will periodically review and evaluate the accumulated data from the trial.

APS ACTION Receives Fridge from APS Foundation of America

July 2012 – The APS Foundation of America donated a fridge to APS ACTION. The fridge will be used at the Hospital for Special Surgery in New York to store specimens for APS ACTION's research projects.

APS ACTION Selects 2012 Young Scholars

July 2012 – Congratulations to the 2012 APS ACTION Young Scholars: Savino Sciascia of St. Thomas Hospital, Cecilia Nalli of the University of Brescia and Stephanie Zuily of Nancy University. The APS ACTION Young Scholar Award is an annual award given to three young physician-scientists in effort to bring new perspective to APS research and encourage young scholars to become involved in the area.

APS ACTION Approves New Members

July 2012 – The APS ACTION Executive Committee selected new members to participate in the clinical research projects. The new members include: Zhuloi Zhang of Beijing University First Hospital, Tatsuya Atsumi of Hokkaido University, Guillermo Ruiz-Irastorza of Hospital Universitario Cruces, Elias Toubi of Bnai-Zion Medical Center and Luis Fernando Penaranda of Hospital Pablo Tobon Uribe.

APS ACTION Holds 2nd Annual Working Meeting

June 2012 – The 2nd Annual APS ACTION Working Meeting took place on June 6, 2012 in Berlin, Germany. Sessions included the Executive Committee report by Doruk Erkan, Core Laboratory Manual Update by Silvia Pierangeli, IRB updates from each center, Institutional Clinical and Material Transfer Agreements, future funding opportunities and the Young Scholar aPL Prevalence project presentation by Laura Andreoli.

APS ACTION Attends National Institute of Health (NIH) Roundtable

May 2012 – APS ACTION members including Doruk Erkan, Steven Levine, Michael Locksin, Tom Ortel and Silvia Pierangeli met with program officers and leadership from several NIH institutes. During the meeting, APS ACTION presented an overview of APS and shared the mission and work of APS ACTION in driving international research efforts.

APS ACTION Selects New Members

March 2012 – The APS ACTION Executive Committee approved the following new members: Danieli Oliveria de Andrade of the University of Sao Paulo, Maria Tektonidou of the University of Athens, Karel de Ceulaer of the University of West Indies and Michelle Petri of Johns Hopkins University.

APS ACTION Presents at National Institutes of Health "Rare Disease Day"

February 2012 – APS ACTION representatives attended and presented a poster at a day-long symposium at National Institutes of Health (NIH) hosted by Office of Rare Diseases Research, National Center for Advancing Translational Sciences, and the NIH Clinical Center. The purpose of the meeting was to celebrate rare diseases research efforts across NIH, the Federal Government, and the advocacy community.

APS ACTION Receives Certificate of Incorporation

February 2012 - A Not-for-Profit Corporation Law certificate was approved for APS ACTION under the 501c3 section of the Not-for-Profit Corporation Law. The certificate will ease the receipt of contributions needed to promote and fund APS ACTION medical research for the prevention and cure of APS.

APS ACTION Launches First Collaborative International Research Projects

January 2012 - Following the APS ACTION Chicago Summit, APS ACTION launched its first two collaborative international projects: 1) a randomized controlled trial of hydroxychloroquine in the primary thrombosis prevention of persistently aPL-positive but thrombosis-free patients without other systemic autoimmune diseases; and 2) a web-based registry of aPL-positive patients with or without systemic autoimmune diseases, which will also include annual blood collection for aPL-testing and future basic science studies.

APS ACTION To Accept New Membership Applications

December 2011 – After repeated requests from other centers, APS ACTION has started accepting applications from new centers that can contribute to its mission. Membership will be decided based on well-defined eligibility criteria that include the APS research interest of centers and their commitment and ability to participate in APS ACTION research activities. Physicians/investigators interested in participating in APS ACTION network should contact JoAnn Vega, CCRC, APS ACTION lead coordinator, at apsaction@info.org.

APS ACTION Convenes 2nd Annual Summit

November 2011 - The 2nd APS ACTION Annual Summit took place in Chicago, IL on November 4-5, 2011. In addition to the APS ACTION Steering Committee Members from 17 medical centers throughout the world, the recipients of the 2011 APS ACTION Young Scholars Award attended, presented and received their awards (Alessandra Banzato, PhD, Cecilia Chighizola, MD, Guilherme de Jesus, MD).

APS ACTION Presents at the American College of Rheumatology Annual Meeting

November 2011 - Two APS ACTION-related presentations were given during the 2011 American College of Rheumatology Scientific Annual Meeting that was held in Chicago, IL on November 5-9, 2011: 1) Antiphospholipid Syndrome Study Group presentation by Doruk Erkan, MD (APS ACTION Executive Committee Chair) about the first year accomplishments of the network; and 2) Clinical Posters Exhibit presentation by JoAnn Vega, CCRC (APS ACTION Lead Coordinator).

APS ACTION Presents at the 8th European Forum on Antiphospholipid Antibodies

September 2011 – Dr Michael D. Lockshin (APS ACTION Executive Committee Member) was invited to Padua, Italy for the 8th European Forum on aPL to present the progress of APS Action, including the background, structure, and future directions of APS ACTION. The purpose of the presentation was to discuss future international collaborations.