Program at a Glance

Updated: 25 March 2021
All speakers and talks are subject to change

All session and presentation times are in the Pacific Time Zone. Presenting author is underlined.

Wednesday, 11 May

Welcome & Scientific Session: Vascular Tumors

08:00 Welcome

08:15 Infantile Hemangioma Masqueraders | Ashley Ng, Eric Monroe, Kara Gill, Catharine Garland, Jason Pinchot, Carol Diamond, Beth Drolet and Lisa Arkin

08:26 Analysis of therapeutic decisions for infantile hemangiomas: A prospective study comparing the Hemangioma Severity Scale with the Infantile Hemangioma Referral Score | Tong Qiu and Yi Ji

08:37 Infantile hemangioma sensitivity to propranolol treatment relies on unique cellular and extracellular features | Sandra Oucherif, Priscilla Kaulanjan-Checkmodine, Sorilla Prey, Muriel Cario-Andé, Christine Léauté-Labreze, Alain Taieb, Hamid Reza Rezvani and Francois Moisan

08:48 Problematic facial infantile hemangiomas | LEI CHANG, QIANYI CHEN, LUQI ZHOU, SHIH-JEN CHANG, YAJING QIU and Lin Xiaoxi

08:59 Non-β-Blocker Enantiomers of Propranolol and Atenolol Inhibit Vasculogenesis in Infantile Hemangioma | Caroline Seebauer, Matthew S. Graus, Lan Huang, Alex McCann, Jill Wylie Sears, Frank Fontaine, Tara Karnezis, David Zurakowski, Steven J. Staffa, John B. Mulliken, Joyce Bischoff and Mathias Francois

09:10 Neurocognitive functioning, physical health, and mental health of school-aged children treated with propranolol or atenolol for infantile hemangioma | Mireille M. Hermans, André B. Rietman*, Renske Schappin*, Peter C.J. de Laat, Elodie J. Mendels, Johannes M.P.J. Breur, Hester R. Langeveld, Saskia N. de Wildt, Corstiaan C. Breugem, Marlies de Graaf, Martine F. Raphael and Suzanne G.M.A. Pasmans

09:21 SEGMENTAL NON-INVOLUTING CONGENITAL VASCULAR ANOMALY WITH ATROPHY, ULCERATION AND SCARRING (SNICVAUS): FURTHER EVOLUTION OF THE SPECTRUM OF
“CONGENITAL HEMANGIOMA” | Marta Ivars, Ilona Frieden, Lauren E. Provini, Lisa Weibel, Martin Theiler, Michel Wassef, Agustina Maria Lanoë, Lara Rodriguez Laguna, Victor Martinez-Glez, Nicole Kittler, Jose Manuel Azaña-Defez, Sarah Chamlin, Beth Drolet, Dariusz Wyrzykowski and Jua

09:32 Segmental infantile haemangioma involving S1 S2 and scalp is the strongest predictor of neurovascular and structural brain anomalies in PHACE syndrome. | Shannon Carter, Nathanael Lucas, Vijeya Ganesan, Neda Alband and Caroline Mahon

09:43 Chronic lymphedema in patients with kaposiform hemangioendothelioma: incidence, clinical features, risk factors and management | Yi Ji

09:54 Large cervicofacial vascular anomaly, a difficult case: Is this a NICH? | Carol MacArthur, Alison Small, Melinda Wu and Gary Nesbit

Scientific Session: Capillary Malformations

10:30 GNA11-mutated Sturge-Weber Syndrome has distinct neurologic and dermatologic features. | Anne Dompmartin, Carine van der Vleuten, Valérie Dekeuleneer, Thierry Duprez, Nicole Revencu, Julie Desir, Leo Schultze Kool, Miikka Vikkula and Laurence Boon

10:41 Phosphorylated-S6 Expression in Sturge-Weber Syndrome Brain Tissue | Meghan McCann, Andrew Cho, Carlos A. Pardo, Thuy Phung, Adrienne Hammill and Anne M. Comi

10:52 Endothelial GNAQ p.R183Q increases angiopoietin-2 and drives formation of enlarged capillary malformation-like blood vessels in mice | Lan Huang, Colette Bichsel, Alexis Norris, Jeremy Thorpe, Sanda Alexandrescu, Anna Pinto, David Zurakowski, Mustafa Sahin, Arin K. Greene and Joyce Bischoff

11:03 Clinical Study on Hemoporfin PDT for Infant Facial Port-Wine Stains | Yunjie Zhang, Hongxia Chen, Shuang Jiang, Lixin Su, Yi Sun, Xindong Fan and Ren Cai

11:14 A Core Outcome domain Set for clinical research on CApillary Malformations (the COSCAM project): an e-Delphi process and consensus meeting | Ginger Beau Langbroek, Albert Wolkerstorfer, Sophie E.R. Horbach, Phylis I. Spuls, Kristen M. Kelly, Susan Robertson, M Ingmar van Raath, Firas Al-Niaimi, Taro Kono, Pablo Boixeda, Hans Joachim Laubach, Ashraf M. Badawi, Agneta Troilius Rubin, Merete Hae

11:25 Shared DECision-making in patients with capillLARy malformATIONs (the DECLARATION-project): preliminary results of a multinational prospective study | Ginger Beau Langbroek, Uzaifa Sheikh, Albert Wolkerstorfer, Sophie E.R. Horbach, Chantal MAM van der Horst and Dirk T. Ubbink
Keynote Address

11:35  Relevance of the phosphoinositide 3-kinase (PI3K) signaling pathway and the development of PI3K pathway inhibitors and metabolic regulation in vascular anomalies.  | Lewis C. Cantley, PhD

Scientific Session: Lymphatic Malformations

13:15  Novel discovery of ROS1:PPFIBP1 fusion protein in General Lymphatic Anomaly  | Angela Kadenhe-Chiweshe, Alain Borzuck, Michael Baad, Bradley Pua and Catherine Mcguinn

13:26  MDFIC mutations cause autosomal recessive Complicated Lymphatic Anomaly  | Alicia B. Byrne, Pascal Brouillard, Drew L. Sutton, Jan Kazenwadel, Saba Montazaribarforoushi, Genevieve A. Secker, Anna Oszmiana, Milena Babic, Kelly L. Betterman, Peter Brautigan, Melissa White, Sandra G. Piltz, Paul Q. Thomas, Christopher N. Hahn, Matthias Rath, Ute Felbor, Christoph G. Korenke, Christopher L. Smith, Kathleen H. Wood, Sarah E. Sheppard, Denise M. Adams, Ariana Kariminejad, Raphaël Helaers, Laurence M. Boon, Nicole Revencu, Lynette Moore, Christopher Barnett, Eric Haan, Peer Arts, Miikka Vikkula, Hamish S. Scott and Natasha L. Harvey

13:37  Detection of PIK3CA mutations in aspirated cyst fluid is comparable to surgically resected tissues: minimally invasive diagnostics for lymphatic malformations  | Dana M. Jensen, Kaitlyn Zenner, Tori T. Cook, Victoria Dmyterko, Randall Bly, Sheila Ganti, Jonathan Perkins and James T. Bennett


13:59  KRAS-driven model of Gorham-Stout disease effectively treated with trametinib  | Anna McCarter, Nassim Homayun Sephr, Raphaël Helaers, Christine Galant, Laurence M. Boon, Pascal Brouillard, Miikka Vikkula and Michael Dellinger

14:10  Lymphatic Endothelial Cell Secretome Negatively Regulates Bone Cell Differentiation and Function  | Ernesto Solorzano, Takhar Kasumov, Michael Kelly and Fayez Safadi

14:21  Dynamic Contrast Enhanced Magnetic Resonance Lymphangiography in Atypical Lymphatic Malformations  | Raj Shaikh

14:32  Fenestration of the lateral wall of the orbit: An easy and safe access to perform sclerotherapy of post-septal orbital macrocystic lymphatic malformations (PSO-MLM)  | Antoine FRAISSENON, Francis FORTIN, Loic VIREMOUNEIX, Arnaud GLEIZAL, Julie PICARD, Pierre BRETON and Laurent GUIBAUD

14:54 Sirolimus for in utero management of a large fetal LM | An Van Damme, Emmanuel Seront, Jean Marc Biard, Sandra Schmitz, Caroline de Toeufl de Toeufl, Philippe Clapuyt, Miikka Vikkula and Laurence M. Boon

15:05 To be confirmed

15:16 The challenges in pediatric primary lymphedema: investigations, genetic findings, clinical features, treatment, and complications. | Catherine McCuaig, Josee Dubois, Julie Powell, Jérôme Coulombe, Niina Kleiber, Louise Caouette-Laberge, Patricia Bortoluzzi, Sandra ondrejchak, Chantal Lapointe and Caroline Colmant

15:27 Lymphedema and Sports: A Case Series of Athletic Patients | Christopher Sudduth and Arin K. Greene

Thursday, 12 May

Scientific Session: Venous Malformations

08:00 Somatic mutations in GJA4 drive venous malformation in the skin and liver, and reveal a novel pathway for therapeutic intervention | Nelson Ugwu, Lihi Atzmony, Katharine T. Ellis, Gauri Panse, Dhanpat Jain, Christine J. Ko, Naiem Nassiri and Keith A. Choate


08:33 To be confirmed

08:44 Treatment of venous malformations: from bench to bedside | Lola Zerbib, Niina Kleiber, Antoine Fraissenon, Paul Isenring, Clement Hoguin, Sophia Ladraa, Quitterie Venot, Charles Bayard, Marina Firpion, Celia Chapelle, Gabriel Morin, Mitchell Braun, Kristin Ammon Shimano, Whitney Eng, Josée Dubois, Laurent Guibaud, Denise M. Adams, Ilona J. Frieden and Guillaume Canaud

08:55 Clinical Utility of Clinical, Radiologic and Histologic Assessment of Verrucous Venous Malformation | Alexandria Brown and Thuy Phung

09:06 Percutaneous sclerotherapy of large venous malformations (VM) using sequential combination of Aetoxisclerol and bleomycin foam (SCABF): A series of 80 procedures with clinical and MR volumetric assessment. | Antoine FRAISSENON, Francis FORTIN, Vincent
DUROUS, Loic VIREMOUNEIX, Arnaud GLEIZAL, Julie PICARD, Pierre BRETON and Laurent GUIBAUD

09:17 SAFETY-EFFICACY OF PERCUTANEOUS INJECTION OF CHITOSAN OR CHITOSAN EMBOLIZING AND SCLEROSING GELS IN A TIE2-ASSOCIATED VM XENOGRAFT MOUSE MODEL | Ricardo Holderbaum do Amaral, Ha-Long Nguyen, Sophie Lerouge, Fatemeh Zehtabi, Arthur Haroutounian, Miikka Vikkula and Gilles Soulez

09:28 Surgical Resection of Labial Venous Malformations: A Single Center Experience | Claire A. Ostertag-Hill, John B. Mulliken, Belinda Dickie and Steven J. Fishman

09:39 Photo-targeted nanoparticle drug delivery systems for venous malformations | Kathleen Cullion, Michelle Pan, Claire Ostertag-Hill and Daniel Kohane

09:50 Use of Alpelisib in Extensive Venous Malformations Refractory to Other Therapies | Whitney Eng, Kristin Shimano, Denise Adams, Mitchell Braun, William Hoffman, Tamjeed Sikder, Sophie Dilek and Ilona Frieden

Scientific Session: Combined Vascular Malformations

10:30 Expanded Genetic Landscape in Complex Vascular Anomalies | Dong Li, Sarah Sheppard, Michael E. March, Christoph Seiler, Lifeng Tian, Mark R. Battig, Leticia S. Matsuoka, Bede N. Nriagu, Nora Robinson, Alexandria Thomas, Erin Pinto, Fengxiang Wang, Cuiping Hou, Renata Pellegrino, Fernanda Thompson, Charlly Kao, Le

10:41 NRAS Q61R Mutation in Human Endothelial Cells Causes Vascular Malformations | Elisa Boscolo, Patricia Pastura, Sandra Schrenk, Jillian Goines, Devin Pillis, Punam Malik and Timothy Le Cras

10:52 Endothelial MAP2K1 Mutation Causes Abnormal Vascular Development in Inducible Mouse Strain | Christopher Sudduth, Patrick Smits, Matthew P. Vivero, Yu Sheng Cheng and Arin K. Greene

11:03 Integration of mRNA/miRNA sequencing and proteomics to identify novel molecular targets in vascular anomalies | Ravi Sun, Haihong Zhang, Stephanie Byrum, Gresham Richter and Graham Strub

11:14 Using spatial transcriptomics in vivo to elucidate pathway alterations in vascular anomalies harboring GNAQ variants | Aman Prasad, Jared Brown, Ashley Ng, Christina Kendziorski, Lisa Arkin and Beth Drolet

11:25 GNAQ mutation in the murine endothelium causes aberrant vascular morphogenesis and KMP that are rescued by MEK inhibition | Sandra Schrenk, Jillian Goines, Sara Szabo and Elisa Boscolo
Proteasome inhibitors effectively inhibit venous and lymphatic malformations | Noa R. Shapiro-Franklin, Emma Iaconetti, Ajit Muley, Hai Li, Charles Karen, Carrie J. Shawber and June K. Wu

Pharmacokinetics of Bleomycin Sclerotherapy in Patients with Vascular Malformations | Joana Mack, Eric Peterson, Shelley Crary, Jeffery Moran, Kathleen Neville and Gresham Richter

Scientific Session: Arteriovenous Malformations

Genotyping and clinical course in 100 patients with arteriovenous malformations. | Lara Rodriguez Laguna, Paloma Triana Junco, Victor Martinez-Glez and Juan Carlos Lopez-Gutierrez

Somatic Mutational Landscape of Extracranial Arteriovenous Malformations and Phenotypic Correlations | Franck-Neil El Sissy, Michel Wassef, Benoit Faucon, Didier Salvan, Sophie Nadaud, Florence Coulet, Homa Adle-Biassette, Florent Soubrier, Annouk Bisdorff Bresson and Melanie Eyries


Activating MAP2K1 Mutation in Zebrafish Endothelial Cells Causes Arteriovenous Shunts | Christopher Sudduth, Nicola Blum, Yu Sheng Cheng, Matthew P. Vivero, Patrick Smits, Nathan D. Lawson and Arin K. Greene

Atypical arterio-venous malformations: different disease? | Giacomo Colletti, Mattia Di Bartolomeo, Sara Negrello, Arrigo pellacani, Gregory Levitin, Linda Rozell-Shannon and Luigi chiarini

Ethanol embolization combined or not with surgery and close clinical follow-up can effectively control extracranial arterio-venous malformations | Ke Chen, Jean-Nicolas Racicot, Josee Dubois, Patrick Gilbert, Patricia Bortoluzzi, Julie Powell, Alain Danino, Marie-France Giroux and Gilles Soulez

To be confirmed

Thalidomide Therapy in Severe Arteriovenous Malformations | Laurence M. Boon, Valerie Dekeuleneer, Julien Coulie, Liliane Marot, Anne-Christine Bataille, Frank Hammer, Philippe Clapuyt, Anne Dompmartin and Miikka Vikkula

Trametinib as a Promising Therapeutic Option in Alleviating Vascular Defects in an Endothelial KRAS-Induced Mouse Model | Ha-Long Nguyen, Laurence M. Boon and Miikka Vikkula

Monocentric Pilot Trial evaluating the safety and efficacy of Trametinib in Arterio-Venous Malformations that are refractory to standard care | Julien Coulie, Emmanuel Seront, Valerie Dekeuleneer, Frank Hammer, Véronique Roelants, Miikka Vikkula and Laurence M. Boon

To be confirmed
### Scientific Session: Multidisciplinary Studies in Vascular Anomalies I

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<tr>
<th>Time</th>
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<th>Presenters</th>
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<tr>
<td>16:00</td>
<td>Assessing the Diagnosis of a Vascular Birthmark, Anomaly, and/or Related Syndrome (VBARS) on the Family</td>
<td>Linda Rozell-Shannon</td>
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<td>16:11</td>
<td>Expansion of Multidisciplinary Vascular Anomalies Center Telehealth Services</td>
<td>Lauren Hill, Taizo Nakano, Aparna Annam, Danielle Katz and Ann Kulungowski</td>
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<td>16:22</td>
<td>To be determined</td>
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<td>17:06</td>
<td>Multimodal Treatment for Fibroadipose Vascular Anomaly: Single-Institution Experience of 106 Cases</td>
<td>Kelly Barry, Marilyn G. Liang and Whitney Eng</td>
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<td>17:17</td>
<td>How “Academic” is ISSVA? Characterization of the Conversion of Meeting Presentation to Publication from the 2016 and 2018 ISSVA Workshops</td>
<td>Norbert Banyi, Sahdev Baweja, Young Ji Tuen, Marija Bucevska and Jugpal Arneja</td>
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### Friday, 13 May

### Scientific Session: Difficult Cases in Vascular Anomalies

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<th>Time</th>
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<td>08:00</td>
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<td>08:11</td>
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<td>08:33</td>
<td>Hypertrophic Progressive Vascular Anomaly due to somatic GNAQ209 mutation with Recalcitrant Ulceration</td>
<td>Lauren Provini, Patricia Cornett, Rachelle Durand, Timothy McCalmont and Ilona Frieden</td>
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Venous malformation with associated segmental overgrowth attributable to mosaic pathogenic deletion in NSD1 gene | Janette diMonda, Anne Gill, Michael Briones, Rachel Swerdlin, Jay Shah, Matthew Hawkins and Rossana Sanchez Russo

Review of the Pre-Congress Day Courses | Dov Goldenberg

A compelling case of extensive VVM that affected breast development | SHIH-JEN CHANG, LIZHEN WANG, YAJING QIU and Lin Xiaoxi

Direct Stick Embolization of a Rectal Venous Malformation via Transanal Minimally Invasive Surgery | Anudeep Yekula, Oluwaseun Ayoade, Vikram Reddy, Haddon Pantel and Naiem Nassiri

A child with a progressive aneurysm syndrome requiring aortoiliac bypass with biallelic variants in LRP1, possible novel arteriopathy gene? | Madison Heisler, Victoria Dmyterko, Dana M. Jensen, Zoe Nelson, Catherine Amlie-Lefond, Patrick Healey, Daniel Hallam, Daniel Miller, Jonathan Perkins and James T. Bennett

To be confirmed

Difficult Case Presentation: Targeted Treatment of an Extensive MAP2K1-Mutant AVM of the Suprahyoid Neck and Face in a 12-Year Old Girl | Joshua Smith, Neeraja Swaminathan, Rajen Mody, Steven W. Pipe, James Bennett, Jonathan Perkins and David Zopf

Scientific Session: Combined Vascular Malformations

Lymphatic Differentiation and Microvascular Proliferation in Vascular Anomalies Lesions Following ISSVA Classification System | Amalia Mulia Utami, Max M. Lokhorst, Mara Kruijt, Onno J. de Boer, Chantal M.A.M. van der Horst and Allard C. van der Wal

Cell-free DNA obtained during sclerotherapy as a novel method for molecular analysis of venous and lymphatic malformations. | Merel Stor, Max M. Lokhorst, Sophie E.R. Horbach, Sanne M. Schreuder, Roy Reinten, Saskia M. Maas, Naomi M. van Hout, Carel J.M. van Noesel and Chantal M.A.M. van der Horst

Benefit of systematic central nervous system screening in capillary malformation-arteriovenous malformation syndrome: an observational study. | Olivia Boccaro, Juliette Mazereeuw, Ludovic Martin, Didier Bessis, Thomas Hubiche, Christine Chiaverini, Anne Dompmartin, Stephanie Mallet, Juliette Miquel, Helene Aubert, Eve Puzenat, Claire Abasq, Laurence Gusdorf, Smail Hadji-Rabia and Annabel Maruani

Parkes Weber Syndrome with Lymphedema Caused by a Somatic KRAS Variant | Whitney Eng, Christopher Sudduth, Dennis Konczyk, Patrick Smits, Steven J. Fishman, Ahmad Alomari, Denise Adams and Arin K. Greene

Targeted medical therapy reduces head and neck PIK3CA-related overgrowth | Madeleine Drusin, Clare Richardson, Jonathan Perkins, Sheila Ganti, Erika Lutsky, Catherine Bull, James
**Preliminary results of the VASE trial evaluating Sirolimus in Vascular Malformations refractory to Standard Care: Beyond the 2-year treatment with sirolimus.**

Emmanuel Seront, An Van Damme, Annouk Bisdorff Bresson, Philippe Orcel, Anne Dompmartin, Marie-Antoinette Sevestre, Philippe Clapuyt, Frank Hammer, Catherine Legrand, Miikka Vikkula and Laurence M. Boon

**EPIK-P1: Retrospective Chart Review Study of Patients With PIK3CA-Related Overgrowth Spectrum (PROS) Who Received Alpelisib**

Guillaume Canaud, Juan Carlos López Gutiérrez, Alan Irvine, Nii Ankrah, Athanasia Papadimitriou, Antonia Ridolfi and Denise M. Adams

**Is there a place for prophylaxis with DOACs in Klippel-Trenaunay Syndrome and other low-flow vascular malformations with intravascular coagulopathy and thromboembolic events?**

Carine van der Vleuten, Lilly Zwerink, Edith Klappe, Elke de Jong and Maroeska te Loo

### Scientific Session: Multidisciplinary Studies in Vascular Anomalies II

**To be confirmed**

**13:41** Intramuscular Vascular Malformations: classification on the basis of clinical-haemodinamic-imaging and histologic findings. Implication on therapeutic approach

Moneghini Laura, Alfredo Zocca, Marcello Napolitano and Gianni Vercellio

**13:52** MENTAL HEALTH EVALUATION IN PATIENTS WITH VASCULAR ANOMALIES

Joana Mack, Tiffany Howell, John Block and Shelley Crary

**14:03** Lymphatic phenotype of Noonan Syndrome: Innovative diagnosis and therapies for lymphatic diseases in Noonan Syndrome

Lotte Kleimeier, Caroline van Schaik, Erika Leenders, Jos M. Draaisma and Willemijn Klein

**14:14** Prospective Observational Study of Pain Severity and Pain Interference Outcomes Following Percutaneous MRI-guided Laser Ablation or Cryoablation for Painful Peripheral, Soft Tissue Vascular Anomalies: 12-month Outcomes

Scott Thompson, Erica M. Knavel Koepsel, Garret M. Powell, Emily C. Bendel, Haraldur Bjarnason, Stephanie F. Polites, Desirae L. Howe-Clayton, Katelyn Anderson, Megha Tollefson and David A. Woodrum

**14:25** Differences in response to low dose sirolimus between children and adults with vascular anomalies?

Veroniek Harbers, Frédérique Bouwman, Lilly Zwerink, Carine van der Vleuten, Bas Verhoeven, Gerard Rongen, Willemijn Klein, Ingrid van Rijnsoever, Leo Schultze Kool and Maroeska te Loo

**14:36** No Association of Sirolimus with Wound Complications in Children with Vascular Anomalies

Steven Mehl, Richard Whitlock, Rachel Ortega, Ionela Iacobas, Renata Maricevich, Tara Rosenberg and Kristy Rialon
14:47  **Clinical Response to PI3K Inhibition in a Cohort of Children and Adults with PIK3CA Related Overgrowth Spectrum (PROS) Disorders** | Alexandra Jane Borst, Prashant Raghavendran, Sharon Albers, Sara Zarnegar-Lumley and James Phillips

14:58  **Safety of Alpelisib in Patients with PIK3CA-Related Overgrowth Spectrum (PROS): Secondary Analysis from the EPIK-P1 Medical Chart Review** | Guillaume Canaud, Denise M. Adams, Alan Irvine, Nii Ankrah, Anthanasia Papadimitriou, Antonia Ridolfi, Fabian Romen and Juan Carlos López Gutiérrez

15:09  **Clinical Characteristics and Management Of Cutaneous Toxicities Associated with the MEK Inhibitor Trametinib** | Tiffany Wu and Joyce Teng

15:20  **Preliminary results from an open-label escalating dose cohort study of VT30 (also known as BBP-681), a topically formulated phosphatidylinositol 3-kinase inhibitor (PI3K), intended as a treatment for patients with cutaneous vascular malformations associat** | Ken Truitt, Lisa Pugliese, Beth Drolet and Eulalia Baselga