FOP DRUG DEVELOPMENT FORUM

DDF

OCTOBER 13-14, 2017

SARDINIA, ITALY

Presented by

IFOPA & FOP Italia

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Welcome!

On behalf of the IFOPA and FOP Italia we are excited to welcome you to the 2017 FOP Drug Development Forum!

For the first time, the Drug Development Forum is being hosted beyond the boundaries of the United States. This is a reflection that our mission to find a cure for FOP is a true global fight. And, we could not have chosen a more serene location than Sardinia.

This is a very exciting time for FOP research and for the broader FOP community. We are rapidly unraveling the mechanisms of FOP and driving towards new treatments for those living with this disease. Global and national clinical trials are now advancing through their development pathways and new FOP discoveries are accelerating. While we are excited with this progress, we also recognize that treatments cannot come soon enough for those living with FOP.

The Drug Development Forum brings together researchers, clinicians and people with FOP into one setting with the common goal of sharing the latest science, tackling new and old challenges, and fostering our research collaboration network. Part of our past success in hosting this meeting was balancing quality academic presentations with interactive and collegial discussions. We have also made a concerted attempt at this year's DDF to leave enough time between sessions to encourage interaction, exchange of ideas, and networking opportunities among all participants. We trust this year's DDF will achieve our goals and will continue to provide a high level of science in a comfortable and enjoyable atmosphere.

We are also excited to meet and welcome many new researchers and pharmaceutical companies into the FOP community. Since our first DDF in 2014, the interest in FOP has grown exponentially. We are seeing progressive increases not only in the number of DDF participants, but also in the number of companies and academic institutions, the number of attendees per institution, and the number of countries represented. While these are great metrics to measure the broadening of FOP research, we also recognize the commitment that each one of you are making by attending this meeting. The FOP community is grateful for your interest, your passion, your work, and your dedication to FOP and making this investment in the Forum! You are the heart of these meetings and your participation helps to make the DDF a success.

We would like to express our thanks to the pharmaceutical and biotech companies for their generous support. We are very grateful to have companies that are committed to developing new treatments for FOP and to providing their financial support for events such as the DDF. Their support has proven invaluable to the planning and execution of this year's Forum.

We hope the 2017 DDF will be another dynamic interaction of dedicated participants. We encourage everyone to participate actively in the discussions over the course of the next two days, and we wish everyone a successful and fruitful meeting.

Best Regards,

Massimo Alfieri
Vice President, FOP Italia

Renata Bocciardi, Ph.D.
FOP Researcher,
University of Genova - G. Gaslini Institute

Betsy Bogard
IFOPA Research Committee Chair

Enrico Cristoforetti
President, FOP Italia

Michelle Davis
Executive Director, IFOPA

Roberto Ravazzolo, M.D.
Professor of Medical Genetics, University of Genova and Chief, Medical Genetics Unit, G. Gaslini Children Hospital

Adam Sherman
Research Development & Partnerships Director, IFOPA

ITINERARY

THURSDAY, OCTOBER 12, 2017

7 to 9 pm **Welcome Dinner**

FRIDAY, OCTOBER 13, 2017

7 to 8:15 am
Breakfast and Networking

8:30 to 9:20 am
Welcome and Opening
Salons de la Infanta and Reina – Ground Floor

9:20 to 11 am
FOP Talks 1: Clinical Investigation of FOP

11 to 11:30 am
Coffee Break and Networking

11:30 am to 1 pm
FOP Talks 2: Receptor Targeting in FOP
Salons de la Infanta and Reina – Ground Floor

1 to 2:15 pm
Lunch and Networking
Restaurant Imperial – 2nd Floor

2:15 pm to 4:05 pm
FOP Talks 3: Building the Foundation for Clinical Advancement
Salons de la Infanta and Reina – Ground Floor

4:05 to 4:40 pm
Updates from International Councils and Consortiums
Salons de la Infanta and Reina – Ground Floor

4:40 to 5:10 pm
Coffee Break and Networking

5:10 to 6:10 pm
Patient Panel: Perspectives on Drug Development
Salons de la Infanta and Reina – Ground Floor

6:10 to 6:20 pm
Day One Closing

7:30 to 9:30 pm
Drug Development Forum Dinner
Restaurant Imperial – 2nd Floor

SATURDAY, OCTOBER 14, 2017

7 to 8:15 am **Breakfast and Networking**

8:30 to 8:40 am
Welcome Back and Opening Remarks
Salons de la Infanta and Reina – Ground Floor

8:40 to 10 am
FOP Talks 4: New Therapeutic Approaches in FOP

10 to 10:15 am
2017 Competitive Research Grant Awards

10:15 to 10:25 am
IFOPA: The Voice of the Community

10:25 to 10:55 am
Coffee Break and Networking

10:55 am to 12:50 pm
Disease Mechanisms with Future impact for Drug Development
Salons de la Infanta and Reina – Ground Floor

12:50 to 2:05 pm
Lunch and Networking
Restaurant Imperial – 2nd Floor

2:05 to 3:05 pm
Drug Development Panel Discussion
Salons de la Infanta and Reina – Ground Floor

3:05 to 3:50 pm
Insights from Other Rare Bone Disorders

3:50 to 4:15 pm
Forum Closing

AGENDA - DAY ONE

Welcome: Thursday, October 12, 2017		
7 to 9 pm	**Welcome Dinner**	
Day One: Friday, October 13, 2017		
7 to 8:15 am	**Breakfast and Networking**	
8:30 to 8:50 am	**Welcome**	
	Along for the Ride	Chris Bedford-Gay, FOP Friends®
	Opening Remarks	Enrico Cristoforetti, FOP Italia and Adam Sherman, IFOPA
8:50 to 9:20 am	**Opening Keynote**	
	Best Practices for Orphan Drug Development	Stelios Tsigkos, M.Sc., M.D., Ph.D., European Medicines Agency
9:20 to 11 am	**FOP Talks 1: Clinicial Investigation of FOP**	
	Palovarotene Program Update	Donna Grogan, M.D., Clementia Pharmaceuticals, Inc. and Fred Kaplan, M.D., The University of Pennsylvania
	A Novel Clinical Study Design to Evaluate Anti-Activin A in FOP	Xiaobing Qian, M.D., Regeneron Pharmaceuticals, Inc.
	Imatinib: A Multi-target Drug for the FOP Tool Kit?	Fred Kaplan, M.D., The University of Pennsylvania
	Investigator Initiated Clinical Trial of mTOR Inhibitor for FOP	Junya Toguchida, M.D., Ph.D., Kyoto University
	Questions & Answers	Moderated by Ben Levi, M.D., University of Michigan
11 to 11:30 am	**Coffee Break and Networking**	
11:30 am to 1 pm	**FOP Talks 2: Receptor Targeting in FOP**	
	Update of ALK2 Blocking Antibody	Take Katagiri, Ph.D., Saitama Medical University
	Hypoxia-selective ALK2 Allosteric Destabilizers/Degraders (H-SAAD/Ds): A Novel Efficacious and Potential Life-long Prophylactic Approach	Jay Groppe, B.A., Ph.D., Texas A&M University College of Dentistry
	Repurposing Saracatnib for FOP*	Alex Bullock, B.A. (Hons), M.A., Ph.D., University of Oxford and Paul Yu, M.D., Ph.D., Harvard Medical School and Brigham and Women's Hospital
	Further Understanding of ALK2 Gain of Function and Allosteric ALK2 Inhibitor Selection*	Alex Bullock, B.A. (Hons), M.A., Ph.D., University of Oxford
	Questions & Answers	Moderated by Eileen Shore, Ph.D., The University of Pennsyvlania School of Medicine
1 to 2:15 pm	**Lunch and Networking**	
2:15 to 4:05 pm	**FOP Talks 3: Building the Foundation for Clinical Advancement**	
	Assessment and Prediction of Joint Dysfunction in FOP	Bob Pignolo, M.D., Ph.D., Mayo Clinic
	Follow-up of 18F NaF PET/CT Imaging in FOP	Marelise Eekhoff, M.D., Ph.D., VU University Medical Center (VUmc)
	Serum Inflammatory Biomarkers in FOP	Ed Hsiao, M.D., Ph.D., University of California, San Francisco
	Effects of Exercise on Tendon Homeostatsis*	Paul Yu, M.D., Ph.D., Harvard Medical School and Brigham and Women's Hospital
	Natural History Study: 12-month Follow-up Data	Ed Hsiao, M.D., Ph.D., University of California, San Francisco
	Prevalence of FOP in France: An Estimate Based on a Record Linkage of Two National Databases	Genevieve Baujat, M.D., M.Sc., Necker Hospital
	Questions & Answers	Moderated by Jim Triffitt, BSc. (Hons); Ph.D., University of Oxford
4:05 to 4:40 pm	**Updates from International Councils and Consortiums**	
	International Clinical Council on FOP (ICC)	Fred Kaplan, M.D., The University of Pennsylvania
	Update From the EU FOP Consortium	Marelise Eekhoff, M.D., Ph.D., VU University Medical Center (VUmc)
4:40 to 5:10 pm	**Coffee Break and Networking**	
5:10 to 6:10 pm	**Patient Panel Discussion**	
	Perspectives on Drug Development	Panelists: Elisa Cristoforetti, Italy; Hugo Fahlberg, Sweden; Nadine Grossmann, Germany; Monica Michelini, Italy; Alessio Perfetto, Italy; Lucy Pratt, United Kingdom Moderated by Massimo Alfieri, FOP Italia and Michelle Davis, IFOPA
6:10 to 6:20 pm	**Day One Closing**	
	Closing Remarks	Betsy Bogard, IFOPA Research Committee
7:30 to 9:30 pm	**Drug Development Forum Dinner**	

* FOP Competitive Research Grant

AGENDA - DAY TWO

Day Two: Saturday, October 14, 2017

7 to 8:15 am	**Breakfast and Networking**	
8:30 to 8:40 am	**Welcome Back**	
	Opening Remarks	Roberto Ravazzolo, M.D., University of Genova and G. Gaslini Institute
8:40 to 10 am	**FOP Talks 4: New Therapeutic Approaches in FOP**	
	Progress on Functional Analyses of TAK1 (TGF-beta Activated Kinase) During HO formation; Efforts to Identify Chemicals That Would Have Potential for Further Drug Development	Yuji Mishina, Ph.D., University of Michigan School of Dentistry
	Development of Antisense-mediated Mutant Allele-specific Knockdown of ACVR1 for the Treatment of FOP*	Toshi Yokota, Ph.D., University of Alberta
	Assessment of FDA-approved Compounds in an In Vitro Osteogenic Model of FOP*	Dimitra Micha, Ph.D., VU University Medical Center (VUmc)
	Role of Rapamycin Treatment and Inflammation on Primary and Recurrent Heterotopic Ossification	Ben Levi, M.D., University of Michigan
	Questions & Answers	Moderated by Coen Netelenbos, M.D., Ph.D., VU University Medical Center (VUmc)
10 to 10:25 am	**The International FOP Association (IFOPA)**	
	2017 FOP Competitive Research Grant Awards	Adam Sherman, IFOPA
	IFOPA: The Voice of the Community	Michelle Davis, IFOPA
10:25 to 10:55 am	**Coffee Break and Networking**	
	Visit the FOP Connection Patient Registry Poster	Neal Mantick, IFOPA
10:55 am to 12:50 pm	**FOP Talks 5: Disease Mechanisms with Future Impact for Drug Development**	
	Registering the Lesion	Aris Economides, Ph.D., Regneron Pharmaceuticals, Inc.
	Activin A and Osteoclast Formation in FOP	Ton Schoenmaker, B.Sc., Academic Center for Dentistry in Amsterdam (ACTA)
	Macrophages and Dipyridamole Counteract Ectopic Bone Development and Restrict the Contribution of Endothelial Progenitors to BMP-mediated Heterotopic Ossification	Silvia Brunelli, Ph.D., University of Milano Bicocca, School of Medicine and Surgery
	Modulating Fibro/Adipogenic Progenitor Behavior as a Mechanism to Ameliorate FOP Pathogenesis	John B. Lees-Shepard, M.S., Ph.D., University of Connecticut
	A Novel Player in the Regulation of Iron Homeostasis Revealed by the Molecular Studies of a FOP Patient	Laura Silvestri, M.D., San Raffaele Scientific Institute
	Does Imbalanced Macrophage Polarization Tip the Scales in FOP?	Dan Perrien, Ph.D., Vanderbilt University Medical Center
	Questions & Answers	Moderated by Paul Yu, M.D., Ph.D., Harvard Medical School and Brigham and Women's Hospital
12:50 to 2:05 pm	**Lunch and Networking**	
2:05 to 3:05 pm	**Panel Discussion**	
	Perspectives on Drug Development	Panelists: Maja Di Rocco, M.D., Giannina Gaslini Institute; Donna Grogan, M.D., Clementia Pharmaceuticals, Inc.; Virginie Hivert, Pharm.D. Ph.D., EURORDIS; Fred Kaplan, M.D., The University of Pennsylvania; Xiaobing Qian, M.D., Regeneron Pharmaceuticals, Inc.; Stelios Tsigkos, European Medicines Agency Moderated by Chris Scott, M.D., University of Cape Town
3:05 to 3:50 pm	**Insights from Other Rare Bone Disorders**	
	Pseudohypoparathyroidism and Progressive Osseous Heteroplasia: Data From the European PHP Network	Giovanna Mantovani, M.D., Ph.D., University of Milan and IRCCS Foundation Ca 'Granda Major Hospital Policlinico
	Progressive Osseous Heteroplasia (POH)	Eileen Shore, Ph.D., The University of Penn School of Medicine
3:50 to 4:15 pm	**Forum Closing**	
	Closing Remarks	Massimo Alfieri, FOP Italia and Adam Sherman, IFOPA
	Together for a Dream	Simona Vallara, FOP Italia

* FOP Competitive Research Grant

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GETTING AROUND THE MEETING

Forum Assistance

Please don't hesitate to reach out to our staff and volunteers with any questions that arise during the Forum.
They can be identified by the purple "VOLUNTEER" and yellow "STAFF" and red "EVENT STAFF" ribbons on their badges.

Should you need further assistance during the FOP Drug Development Form, please see a representative with Bishop-McCann or contact Michelle Davis, IFOPA Executive Director, at +1. 816.809.2772 cell.

Registration/Attendee Services Desk

The Registration/Attendee Services Desk will be located on the ground level. The desk will be open during the following days and hours:

Thursday, October 12	11 am – 9 pm
Friday, October 13	7 am – 9:30 pm
Saturday, October 14	7 am – 4:30 pm

Presenters Sound and Stage Check

There will be the opportunity for you to do a stage and sound check (if required) in Salons de la Infanta and Reina on the ground floor at the following times:

Friday, October 13	7 – 8 am and 6 – 7 pm
Saturday, October 14	7 – 8 am

Your contact onsite will be Vicky Fairhurst who can be reached at +1.310.980.1987. She will be managing all speakers and will be available to assist with content and rehearsals as needed.

Wireless Connections

Complimentary internet service is available to you throughout the hotel and in your guest room; no code is necessary.

Luggage Storage for Departure

On your departure day, your bag can be held in the hotel's luggage room or the ground floor. This service is provided free of charge.

Event Feedback

An event survey will be sent to you following the meeting. We ask that you provide us with the valuable feedback that will help to make the next Forum even better. Your participation is appreciated.

Thank you!

FORUM ATTENDEE LIST

NAME	ORGANIZATION(S)	COUNTRY
Carolina Acquaviva, M.Sc.	Hospital Israelita Albert Einstein	Brazil
Mona Al Mukaddam, M.D., M.S.	The University of Pennsylvania	United States
Eleonora Alfieri	FOP Italia Onlus	Italy
Isabella Alfieri	FOP Italia Onlus	Italy
Massimo Alfieri	FOP Italia Onlus IFOPA Research Committee IFOPA International President's Council	Italy
Paolo Arrigoni, M.D.	University of Pavia	Italy
Jim Baker	Blueprint Medicines	United States
Tiziano Bandiera, Ph.D.	Italian Institute of Technology	Italy
Genevieve Baujat, M.D., M.Sc.	Necker Hospital	France
Chris Bedford-Gay, B.Sc.	FOP Friends® UK IFOPA Board of Directors IFOPA International President's Council	United Kingdom
Anna Belyaeva	FOP Russia	Russia
Staffan Berglund, M.D., Ph.D.	Umeå University Hospital	Sweden
Marta Bertamino, M.D.	Giannina Gaslini Institute	Italy
Fabio Bertozzi, Ph.D.	Italian Institute of Technology	Italy
Doris Bianchi	FOP Italia Onlus	Italy
Renata Bocciardi, Ph.D.	University of Genova and G. Gaslini Institute	Italy
Betsy Bogard, M.S.	IFOPA Research Committee	United States
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Esmée Botman, M.D.	VU University Medical Center (VUmc)	The Netherlands
Elinor Bouvy-Berends, D.D.S.	Dutch FOP Foundation IFOPA International President's Council	The Netherlands
Nathalie Bravenboer, Ph.D.	VU University Medical Center (VUmc)	The Netherlands
Silvia Brunelli, Ph.D.	University of Milano Bicocca, School of Medicine and Surgery	Italy
Roberto Bufo, M.D.	A.S.L. Foggia Italian Progressive Osseous Heteroplasia Association (IPOHA Onlus)	Italy
Alex Bullock, B.A. (Hons), M.A., Ph.D.	University of Oxford	United Kingdom
Francesco Caforio	FOP Italia Onlus	Italy
Amanda Cali	International Clinical Council on FOP	United States
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Elena Canova	FOP Italia Onlus	Italy
Yulin Chen, Ph.D.	Shanghai Children's Medical Center, Shanghai Jiao Tong University School of Medicine	China
Angela Cheung, M.D., Ph.D., FRCPC, CCD	University Health Network	Canada
Lucia Chidichimo	FOP Italia Onlus	Italy
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Carmen De Cunto, M.D.	The Italian Hospital of Buenos Aires	Argentina
Anna De Poli	FOP Italia Onlus	Italy
Patricia Delai, M.D.	Hospital Israelita Albert Einstein FOP Brasil IFOPA International President's Council	Brazil
Maja Di Rocco, M.D.	Giannina Gaslini Institute	Italy
Stephen Donahue, M.D.	Regeneron Pharmaceuticals, Inc.	United States
Margarita Dubko, M.D.	Saint-Petersburg State Pediatric Medical University	Russia
Aris Economides, Ph.D.	Regeneron Pharmaceuticals, Inc.	United States
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Yonghwan Kim, Ph.D.	Sookmyung Women's University	South Korea
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Paolo Odisio	FOP Italia Onlus	Italy
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Maurizio Pacifici, Ph.D.	The Children's Hospital of Philadelphia	United States

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Amy Wilson, Ph.D.	Clementia Pharmaceuticals, Inc.	United States
Pam Yelick, Ph.D.	Tufts University	United States
Lei Yin, M.D., Ph.D.	Shanghai Children's Medical Center, Shanghai Jiao Tong University School of Medicine	China
Toshifumi Yokota, Ph.D.	University of Alberta	Canada
Rika Yokota-Maruyama, Ph.D.	University of Alberta	Canada
Paul Yu, M.D., Ph.D.	Harvard Medical School and Brigham and Women's Hospital	United States
Lara Zavoli	FOP Italia Onlus	Italy
Alessandro Zorzi, M.D., M.Sc., Ph.D.	Campinas State University (UNICAMP)	Brazil

SPEAKER BIOGRAPHIES

Massimo Alfieri*

Vice President
FOP Italia Onlus

Massimo became a member of FOP Italia Association after his younger daughter, Isabella, was diagnosed with FOP in 2009, when she was 12 years old. He has served the Italian organization contributing to the Board of Directors activity and, together with his wife Simona and daughter Eleonora, promoting a series of fundraising efforts and media opportunities for FOP awareness. Massimo has given special support to FOP Italia in planning the annual scientific FOP conference, gathering the best worldwide experts in research and clinic of the pathology. He is currently taking care of the international relations with the other FOP national associations, and specifically with the IFOPA. Since 2016, he is also member of the IFOPA Research Committee. Massimo received a degree in Electric Engineering at the University of Bologna in 1984, and a Master in Professional Counselling in 2010. He is currently working as Management Consultant and Project Director for some European Industries active in the pharmaceutical sector.

Genevieve Baujat, M.D., M.Sc.

Medical Geneticist Consultant
Necker-Enfants Malades Hospital

Genevieve Baujat is a pediatrician by training and works currently as a Medical Geneticist Consultant in the Centre of Reference for Skeletal Dysplasia in the Imagine Institute of Necker-Enfants Malades Hospital, Paris, France. She is a member of the BOND Rare Bone Disease ERN. She has an active interest in the diagnosis of skeletal congenital disorders (from antenatal period to adulthood) and in the follow-up and management of children with such conditions. She participates in several research projects through the Centre of Reference, and was particularly involved in the development of the national French database for rare diseases named CEMARA, working also on epidemiological aspects of skeletal disorders. She is an investigator for several clinical trials for natural history studies and innovative therapies, including FOP.

Chris Bedford-Gay, B.Sc.

Chairman and Dad to Oliver age 9 with FOP
FOP Friends®

From the moment I received Oliver's diagnosis at age 1, I became heavily involved in the search for a treatment/cure for FOP in any way I could. In addition to founding FOP Friends®, I served as chairman of FOP Action (which has now been integrated into FOP Friends®), continue to serve on the board of the International FOP Association (IFOPA) where my first challenge was the technical development of the FOP Flare-Up Survey. I have been a board member for 6 years and I am current chairman of the International President's Council, a role dedicated to bringing together FOP organizations and leaders from across the world. I also represent the UK FOP community internationally. I do this alongside my day-job as director of UK-based technology company, Skillsarena, and of course alongside being the father of three boys, Oliver age 9 (with FOP), Leo age 7 and Harry age 4.

*Session Moderator

SPEAKER BIOGRAPHIES

Renata Bocciardi, Ph.D.

Researcher
DINOGMI, University of Genoa Medical Genetics Unit, G. Gaslini Institute

Dr. Bocciardi is researcher at the University of Genoa with a background in molecular and cell biology with specific training in molecular and medical genetics. Dr. Bocciardi is a faculty member for Medical Genetics teaching at the Medical School (University of Genoa) and at the School of Biological Sciences (University of Genova). Since the beginning of her career she has been involved in research aimed at identifying the genetic basis and pathogenic mechanisms of rare genetic disorders. She became involved in FOP in 2007 starting by providing the molecular genetic testing for the Italian patients and then by getting involved in research focused on the regulatory mechanisms intervening in the control of the ACVR1 gene expression both at transcriptional/post-transcriptional level and the BMP-mediated downstream pathway. Starting from this research, more recently, her group has developed developed cell-based assays useful to realize high capacity screening of chemical compounds to target ACVR1 mediated pathway at different levels, with the aim to contribute to the identification of new therapeutical strategies for FOP.

Since the beginning of her activity in FOP field she has a strong, active and unique collaboration with FOP Italia gathering the Italian FOP patients and their families. She coordinates the experimental work of a research group and she has published over 48 papers.

Betsy Bogard

Chair, Research Committee
International FOP Association

Betsy Bogard works in the rare disease community to support development of transformative therapies. She currently leads real-world evidence generationat Bluebird Bio, a clinical-stage biotechnology company in Cambridge, Massachusetts developing gene therapy for severe genetic and rare diseases. She also holds a volunteer position as Chair of the Research Committee at the IFOPA, a nonprofit patient organization for the rare disease fibrodysplasia ossificans progressiva (FOP). Ms. Bogard has nearly 20 years of experience in biotechnology in areas that include real world evidence, health economics, program management and patient advocacy. She has a master's degree in health policy and management from the Harvard School of Public Health. Ms. Bogard lives in Somerville, Massachusetts with her husband and two sons. Her younger brother, Jud, has FOP.

Silvia Brunelli, Ph.D.

Associate Professor
University of Milano Bicocca, School of Medicine and Surgery

Born in 1969, Professor Brunelli was awarded her Degree in Biology at the University of Milan in 1993. After receiving her Ph.D. in Cell and Molecular Biology (Open University, UK, 1998) she won a EC Marie Curie fellowship in 1997 and moved to London, UK, for her postdoctoral training at the MRC-National Institute for Medical Research, until 2001. From 2001 to 2005, she was postdoctoral Scientist at San Raffaele Research Institute, Milan, Italy, then Assistant Professor in Cell Biology at the University of Milano Bicocca, Milan, Italy until 2015. She was also Group leader in the Division of Regenerative Medicine, San Raffaele Scientific Institute from 2007 to 2015. Professor Silvia Brunelli is now Associate Professor of Cell and Molecular Biology at the University of Milano Bicocca, Milano and head of the Laboratory of Stem Cell and Muscle Regeneration in the Department of Medicine and Surgery. The large majority of her research activity has been dedicated to muscle development and physiopathology, focusing on the molecular and cellular characterization of the regenerative muscle niche and she has also collaborated to the development of experimental therapeutic strategies to muscle degenerative disorders combining pharmacological and stem cell approaches in animal models.

SPEAKER BIOGRAPHIES

Alex Bullock, B.A. (Hons), M.A., Ph.D.

Principal Investigator at Structural Genomics Consortium (SGC)
University of Oxford

Dr. Bullock is a Principal Investigator at the Structural Genomics Consortium (SGC) based at the University of Oxford, UK. The SGC is a public-private partnership that aims to provide open access chemical tools and structural knowledge to accelerate drug discovery. Dr. Bullock heads the SGC's Growth Factor Signalling Group as well as the University of Oxford FOP Research Team. He became involved in drug development for FOP in 2006 when the causative gene ACVR1 was identified. Since then his group has solved the crystal structure of the corresponding ALK2 protein in complex with a large number of small molecule inhibitors. Dr. Bullock trained in molecular biology at the University of Cambridge, UK. He held a Wellcome Trust Postdoctoral Fellowship at the University of Washington, Seattle, and later at the University of Oxford where he studied the regulation of HIF-1alpha in hypoxia. He joined the SGC for its launch in 2004. He has published over 50 scientific papers and reviews.

Enrico Cristoforetti

President
FOP Italia Onlus

Enrico Cristoforetti lives in Italy, and is the founder and president of FOP Italia. He established FOP Italia in 2006 after his young daughter was diagnosed with FOP. Over the years, FOP Italia has organized and held annual conferences which have been attended by respected FOP researchers and many individuals with FOP and their families. Attendees have traveled from many countries outside of Italy including Holland, Austria, Russia, South Africa, Australia, Sweden, the UK, France and Argentina. With the driving force of Enrico's leadership efforts behind it, the Italian FOP organization has been active in raising funds for FOP research, and successfully obtaining tax funds available for non-governmental organizations in Italy. Incredibly, FOP Italia has even established and presently fund a small FOP research group at Genova, Italy. In 2014, he received the Jeannie Peeper Outstanding International Leadership Award.

Michelle Davis*

Executive Director
International FOP Association

Michelle joined the IFOPA as Executive Director in February 2016. The majority of her career has been spent working in the nonprofit sector; seven years of which were spent leading a nonprofit chamber of commerce training and consulting with local nonprofit staff, boards of directors and volunteers. In that role, Michelle was exposed to many deserving causes, but her passion has always been in working with national voluntary health agencies, including tenures at the National Kidney Foundation and Polycystic Kidney Disease (PKD) Foundation. While at the PKD Foundation, Michelle became acquainted with the rare disease community which is part of what drew her to the IFOPA. At the PKD Foundation, Michelle served in the role of Chief Development Officer where she worked in all aspects of fundraising and maintained the organization's relationships with industry. Michelle also led the organization's education and advocacy initiatives, including organizing patients for an FDA Advisory Committee meeting for the review of the first-ever treatment for PKD, tolvaptan. At the IFOPA, Michelle is partnering with the Board of Directors to develop the organization's strategic plan and corresponding fundraising, marketing and communications and advocacy and awareness plans. She is also leading the development of family programs and services to better serve and connect the FOP community.

*Session Moderator

SPEAKER BIOGRAPHIES

Maja Di Rocco, M.D.

Head of the Unit of Rare Diseases
Department of Pediatrics, IRCSS Giannina Gaslini

Maja Di Rocco is Head of the Unit of Rare Diseases at the Department of Pediatrics, IRCSS Giannina Gaslini in Genoa, Italy and Professor on contract of Metabolic Diseases at the Postgraduate School of Pediatric and Pediatric Neurology and Psychiatry at the University of Genoa. She obtained her degree in Medicine and Surgery at the University of Genoa, where she went on to do a postgraduate degree in Pediatrics and a postgraduate degree in Pediatric Neurology and Psychiatry. She has served a fellowship in 1986 at the Department of Neurology, Columbia University, New York, USA. She is a member of the Society for the Study of Inborn Errors of Metabolism, the Italian Society of Pediatrics, the Italian Society of Human Genetics and the Italian Society for the Study of Hereditary Metabolic Diseases. Her research areas include biochemical and molecular bases of inborn errors of metabolism, therapy of lysosomal diseases, and molecular bases of genetic diseases. She has published over 220 original articles on metabolic and genetic subjects in peer-reviewed journals.

Aris Economides, Ph.D.

Executive Director
Regeneron Pharmaceuticals, Inc.

Dr. Aris N. Economides received his Ph.D. in Biochemistry from Michigan State University in 1992, and promptly joined Regeneron Pharmaceuticals. He currently holds the position of Executive Director, leading two groups: Genome Engineering Technologies and the Skeletal Diseases Therapeutic Focus Area. In addition, he is a co-founder of Regeneron Genetics Center (RGC), where he is also Head of Functional Modeling. Dr. Economides co-invented Cyto-kine Traps, VelociGene®, and VelocImmune®, all part of an integrated methodology for target discovery, validation, and the generation of biologic drugs such as the IL1 and VEGF traps, as well as therapeutic antibodies. As part of his involvement with the RGC, Dr. Economides has been working to elucidate the molecular pathophysiology of Mendelian disorders. A recent example is his work in fibrodysplasia ossificans progressiva, where he and his team discovered a novel mechanism that explains important aspects of FOP's pathophysiology and pinpoints a new potential route to therapy.

Marelise Eekhoff, M.D. Ph.D.

Internist Endocrinologist
VU University Medical Center (VUmc)

Marelise Eekhoff is internist-endocrinologist, working as staff member at the department of Internal Medicine section Endocrinology of the VU University Medical Center (VUmc), Amsterdam, The Netherlands. The section of endocrinology has a long record in bone research, many studies/trials have been and are being performed. Marelise completed her internal medical training at the Leiden University Medical Center (LUMC), The Netherlands. Subsequently, she was fellow staff member at the department of Intensive Care, followed by her endocrinology training at the department of Endocrinology of the LUMC. In the same period she performed her dissertation "Paget's disease of the bone in The Netherlands: Epidemiology, Genetics and Treatment". She is focusing on the mineral rare bone-endocrine disease, including outpatient-clinical care, education and research. Several grants were obtained and PhD students graduated.

Area of special expertise is fibrodysplasia ossificans progressiva (FOP). Since 2015, the VUmc is the Dutch expert centre in FOP (next to other rare bone diseases). A dedicated multidisciplinary team (15 disciplines) has been formed regarding the care of FOP in the VUmc. In 2012, the European FOP consortium has been established at the VUmc in Amsterdam including health care providers, researchers and patient organizations of more than 10 European countries. Several European and international collaborations are ongoing since. In the VUmc, five collaborating laboratories (including ACTA, Amsterdam) are dedicated to FOP research which has resulted in two human FOP cell culture models. In addition, in collaboration with the innovative imaging center of the VUmc, a diagnostic imaging tool to follow the activity of flare-ups in FOP has been developed. A close collaboration between the VUmc clinical care as research and the Dutch FOP patient organization exists.

SPEAKER BIOGRAPHIES

Donna Grogan, M.D.

Chief Medical Officer
Clementia Pharmaceuticals, Inc.

Dr. Grogan is Chief Medical Officer at Clementia Pharmaceuticals with over 20 years of experience in the phamaceutical industry, and is a board certified internal medicine physician with 15 years of experience in clinical medicine. During her time in industry, she has led numerous investigational new drug applications, design and execution of clinical programs and new drug applications across multiple therapeutic areas including respiratory, cardiovascular, and orphan diseases. Dr. Grogan has been involved with multiple high-profile product approvals including Lunesta®, Xopenex HFA®, Brovana™ and most recently the EMA authorization of Vyndaqel® (tafamidis) for the treatment of the rare neurologic disease Transthyretin Familial Amyloid Polyneuropathy. Over the past 10 years her work has focused almost exclusively in rare diseases. Dr. Grogan has extensive experience with international regulatory authorities, including the U.S. Food and Drug Administration (FDA), European Medicines Agency (EMA) and the Pharmaceuticals and Medical Devices Agency (PMDA), Japan.

Jay C. Groppe, B.A., Ph.D.

Associate Professor
Biomedical Sciences, Texas A&M University College of Dentistry

Dr. Groppe earned bachelor's and doctoral degrees in Biochemistry – Molecular Biology at the University of California (Santa Barbara), continued by one year of postdoctoral training with a renowned synthetic organic chemist, T.C. Bruice. Seven years' experience at one of the top institutes in Europe (Biozentrum, University of Basel, Switzerland) expanded his scope to encompass developmental biology, the origin of his focus over the last nearly twenty-five years on the structure and function of components of BMP signaling. A subsequent three years as a visiting scientist at the Salk Institute (La Jolla, CA) culminated in an article in the British journal *Nature* (Dec 2002) on the structural basis of BMP signaling inhibition by the secreted antagonist Noggin, in collaboration with Aris Economides at Regeneron. A semi-independent position followed at the UT Health Science Center (San Antonio) that led to another high-profile contribution, the structural basis for cooperative assembly of the extracellular TGF-b signaling complex.

In 2007, a year after solicitation to collaborate by Drs. Kaplan and Shore, Professor Groppe was recruited by Texas A&M University College of Dentistry (Dallas, TX), where he was the first to identify the structural element disrupted by the recurrent ALK2 mutation from a highly reliable ALK5 structure-based homology model later confirmed at SGC Oxford (2007), similarly examined the structural basis of dysregulation from variant mutations (2009), accurately quantitated the diminished binding by FKBP12 to the recurrent mutant receptor (2011), described the functional consequences of the most severe variant to date (2015), co-authored a report on the role of hypoxia in FOP (2016), and after a decade of meticulous and systematic dissection, elucidated the allosteric nature of the Arg206His ALK2 receptor kinase mutation, which in turn has lead to his development during the last 4+ years of hypoxia-selective ALK2 allosteric destabilizers and degraders (H-SAADDs) that trigger destruction of the aberrant receptor kinase at the lower pH of hypoxic tissue in FOP lesions (topics presented in tandem at Oct 2016 BMP Conference, Harvard Medical School).

SPEAKER BIOGRAPHIES

Virginie Hivert, Pharm.D. Ph.D.

Therapeutic Development Director
EURORDIS

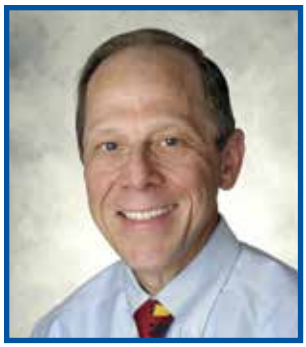
Virginie Hivert joined EURORDIS in 2014 as Therapeutic Development Director. Virginie is responsible for following the development of orphan drugs as an observer on the Committee for Orphan Medicinal Products at the European Medicines Agency. She coordinates the group of high-level EURORDIS representatives/ volunteers who sit on the various scientific committees/working parties at the EMA, known as the Therapeutic Action Group (TAG). She is responsible for two activity areas in EURORDIS, one being the training of patients' representatives in therapeutic development activities (EURORDIS Summer School, EUPATI) and the other related to their engagement in these activities (in Protocol Assistance in Scientific Advice Working Party (SAWP) at the EMA for example). She is Vice-Chair of the Therapies Scientific Committee of IRDiRC (International Rare Disease Research Consortium). Prior to joining EURORDIS, Virginie worked for Orphanet as coordinator of data collection of the resources related to rare diseases (such as expert centers, medical laboratories, patient organizations, research projects, clinical trials, etc.) in the 37 countries of the Orphanet Consortium. Virginie holds a PharmD and a PhD in Biological Sciences and has previously worked in basic research, particularly on pathophysiological pathways in oncology.

Ed Hsiao, M.D., Ph.D.

Associate Professor
University of California, San Francisco (UCSF)

Ed completed his M.D. and Ph.D. at the Johns Hopkins Medical School studying hormone signals in tissue injury and repair. After completing his internal medicine residency at Johns Hopkins, Ed went to UCSF for his endocrinology fellowship, focusing on the roles of hormones and genetics in skeletal diseases. He is currently an Associate Professor at UCSF in the Division of Endocrinology and Metabolism and in the Institute for Human Genetics.

Ed's research is driven by a bedside-to-bench-to-bedside approach, using clinical observations and patient samples to inspire the research with the long-term goal of improving the care of patients with all types of skeletal disorders. His laboratory uses human stem cell and mouse models as well as genomic studies to elucidate how G-protein coupled receptors (GPCRs) and bone morphogenetic proteins (BMPs) specify the formation of key tissues such as bone, cartilage, muscle, and fat. Ed's lab is using human induced pluripotent stem cells and genetics to elucidate the mechanisms involved in FOP. He also sees patients with metabolic bone diseases, including FOP, in the UCSF Metabolic Bone Clinic. Finally, he is the primary investigator at the University of California, San Francisco site for the Clementia clinical studies in FOP.



Fred Kaplan, M.D.

Isaac and Rose Nassau Professor of Orthopaedic Molecular Medicine in Orthopaedic Surgery
University of Pennsylvania

Dr. Fred Kaplan is the Isaac and Rose Nassau Professor of Orthopaedic Molecular Medicine and Chief of the Division of Orthopaedic Molecular Medicine at the Perelman School of Medicine at the University of Pennsylvania. Dr. Kaplan co-directs the Center for Research in FOP and Related Disorders and "is recognized as the world's leading expert on genetic disorders of heterotopic ossification and skeletal metamorphosis." In 1997, Dr. Kaplan was awarded the first endowed chair in the USA for orthopaedic molecular medicine. In 2006, Newsweek named Dr. Kaplan as one of "15 people who make America great." In 2009, Dr. Kaplan was elected to the Institute of Medicine, an organization established by the United States National Academy of Sciences to honor professional achievement in the health sciences.

SPEAKER BIOGRAPHIES

Takenobu Katagiri, Ph.D.

Professor and Division Head of Division of Pathophysiology
Research Center for Genomic Medicine, Saitama Medical University

Takenobu Katagiri is Professor and Division Head of Division of Pathophysiology, Research Center for Genomic Medicine, Saitama Medical University. He started his scientific career on BMPs in 1987, when he was a graduate student of Kitasato University. He received his Ph.D. degree at Graduate School of Pharmaceutical Sciences, Kitasato University in 1992. He has established an in vitro model system of osteoblastic differentiation of C2C12 myoblasts induced by BMP signaling. He is interested in molecular mechanisms of physiological and pathological skeletal development in soft tissues through BMP signaling.

John B. Lees-Shepard, M.S., Ph.D.

Postdoctoral Fellow
University of Connecticut

John B. Lees-Shepard is currently a postdoctoral fellow under the guidance of Dr. David J. Goldhamer. Throughout his training, Dr. Lees-Shepard has investigated the mechanisms by which progenitor cell populations contribute to distinct aspects of limb skeletal development and disease. Dr. Lees-Shepard's Ph.D. thesis investigated mechanisms underlying endochondral bone formation and osteoarthritis pathogenesis. This work focused on characterizing articular cartilage progenitor cells and identifying factors that promote their activation and expansion. A major component of Dr. Lees-Shepard's current research is the identification and characterization of muscle-resident progenitor cell populations responsible for genetic and injury-induced forms of heterotopic ossification. This research synergizes with ongoing industry collaborations established in Dr. Goldhamer's lab and is supported by the State of Connecticut Regenerative Medicine Research Fund.

Benjamin Levi, M.D.*

Director, Burn/Wound and Regenerative Medicine Laboratory
Assistant Professor in Surgery
Director Scar Rehabilitation Program
University of Michigan

Dr. Levi is a surgeon scientist who completed his undergraduate education at Washington University, medical school at Northwestern University, Plastic and Reconstructive Surgery residency at the University of Michigan and fellowship in Burn Surgery/Surgical Critical Care at Massachusetts General Hospital. During his residency, he also completed a post-doctoral research fellowship at Stanford University.

Inspired by his experience as a patient enrolled in a clinical trial and his work in a wound healing laboratory in high school and college, Dr. Levi has remained active in research throughout his career. During his post-doctoral fellowship, he focused on stem cell biology, mesenchymal cell osteogenesis, and bone tissue engineering. Since returning to the University of Michigan four years ago, Dr. Levi founded the Burn/Wound and Regenerative Medicine Laboratory. This lab focuses on the significant clinical problem of heterotopic ossification. Specifically, Dr. Levi has developed animal models to study this complex process and is working to improve early diagnostic and treatment modalities. Thanks to the support of the IFOPA and close collaborations with Dr. Mishina and Dr. Schipani, this laboratory has been able to expand their studies into the area of hypoxia inducible factor 1 alpha and its role in traumatic HO and FOP.

*Session Moderator

SPEAKER BIOGRAPHIES

Neal Mantick

FOP Connection Registry Study Manager
International FOP Association

Neal Mantick is an independent consultant who has nearly 30 years of experience in pharmaceutical research. For the past 20 years, Neal's focus has been in the design and management of a wide variety of global patient registries sponsored by biopharmaceutical companies and patient advocacy groups. These programs have helped to improve the understanding of rare diseases and to expand physicians' and patients' access to new, innovative drug products and medical devices. His recent positions included leadership roles with NovusLife LLC, PAREXEL International, Abt Bio-Pharma Solutions and the Genzyme Corporation. He received a BS degree in Pharmacy from the University of Kentucky and a M.S. degree in Health Policy and Management from the Harvard T.H. Chan School of Public Health. Neal is a contributing author to Registries for Evaluating Patient Outcomes, sponsored by the Agency for Healthcare Research and Quality, and to the International Society for Pharmacoeconomics and Outcomes Research's Taxonomy of Patient Registries: Classification, Characteristics and Terms. He has also been a featured speaker at a number of conferences on registry study design and drug development research.

Giovanna Mantovani, M.D., Ph.D.

Associate Professor of Endocrinology
University of Milan; Fondazione IRCCS Ca' Granda Ospedale Maggiore Policlinico

Giovanna Mantovani obtained her M.D. at the University of Milan in 1998, followed by the Specialty in Endocrinology and Metabolism in 2003 and she then obtained a Ph.D. in Molecular Medicine in 2007 (University of Milan). She is now an Associate Professor of Endocrinology at the University of Milan and Head of the "Referral Center for the Study and Care of Pituitary Tumors" at Fondazione IRCCS Ca' Granda Policlinico in Milan.

In the past 15 years, her research has been focusing on 3 main topics: 1) the study of the role played by the cAMP/PKA cascade in the control of proliferation of tumoral endocrine and endocrine-related cells, 2) the study of the relationship existing between GNAS-related diseases and the regulation of transcription of the Gs alpha gene in humans, and 3) the clinical and molecular characterization of pseudohypoparathyroidism and GNAS-related disorders.

Since 2000, she has made important contributions to the characterization of Gsα expression and imprinting in human endocrine tissues, as well as the clinical and molecular characterization of patients with related rare metabolic disorders. From a translational point of view, the demonstration of Gsα imprinting in the human pituitary has led to our first description of GH deficiency due to GHRH resistance in patients with Pseudohypoparathyroidism and to the subsequent publication of the first series of patients treated with rhGH.

She is a member of the Euro-PHP consortium for (epi)genetic diagnosis of Pseudohypoparathyroidism and the EU COST- BM1208 program European Network for Human Congenital Imprinting Disorders.

Dimitra Micha, Ph.D.

Principal Investigator
VU University Medical Center (VUmc)

Dr. Dimitra Micha is, since 2016, the Principal Investigator of the Centre for Connective Tissue Disorders at the VU University Medical Center in Amsterdam. In 2009, she completed her Ph.D. at the Paterson Institute for Cancer Research UK after which she moved to the VU University Clinical Genetics department to work in the field of connective tissue disorders for 6 years. The focus of her research is osteogenesis imperfecta, hereditary osteoporosis and fibrodysplasia ossificans progressiva as well as syndromic types of thoracic aortic aneurysms. She investigates new genetic causes and aims to unravel the molecular mechanism leading to disease presentation. The last years her research has focused on the identification of new therapeutics which are severely lacking for these rare patient groups. She has pioneered in developing novel in vitro models based on cell transdifferentiation serving as platform for small molecule screening.

SPEAKER BIOGRAPHIES

Yuji Mishina, Ph.D.

Professor
University of Michigan School of Dentistry

Education and Advanced Training:
1983-1986 Ph.D. University of Tokyo, Tokyo, Japan (Molecular Biology)

1981-1983 MS University of Tokyo, Tokyo, Japan (Molecular Biology)

1977-1981 BS University of Tokyo, Tokyo, Japan (Biology)

Academic Appointment:
1992-1998 Postdoctoral Fellow with Dr. Richard Behringer,

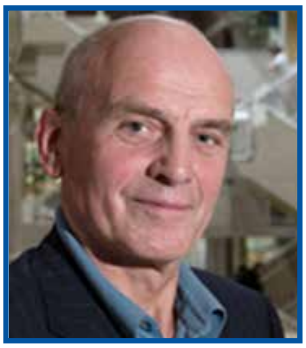
The University of Texas, M.D. Anderson Cancer Center, Texas

1998-2008 Group Head, Laboratory of Reproductive and Developmental Toxicology, National Institute of Environmental Health Sciences, National Institutes of Health, Research Triangle Park, NC

2008-2014 Associate Professor, University of Michigan, School of Dentistry, Department of Biologic and Materials Sciences, Ann Arbor, MI

2014-Present Professor, University of Michigan, School of Dentistry, Department of Biologic and Materials Sciences, Ann Arbor, MI

The Mishina Lab is interested in functions of BMP signaling during mouse embryogenesis, craniofacial development and bone remodeling. The lab has been generating genetically modified mouse lines that can conditionally upregulate or downregulate BMP signaling. Using these resources, the lab is actively investigating the roles of BMP signaling in neural crest cell differentiation, osteoblast-osteoclast interactions and heterotopic ossification.



Coen Netelenbos, M.D., Ph.D.*

Emeritus Professor of Endocrinology
VU University Medical Center (VUmc)

Graduate 1961-1969; 1975 internist-endocrinologist,1977 Ph.D. thesis in Medicine: parathyroid function in urolithiasis, 2000 Head Dept. Endocrinology, 2002 full professor. Since 1977 patient care and research randomized clinical trials with oestrogen, selective oestrogen receptor modulators SERM's and several bisphosphonates in osteoporosis, Crohn's disease and cognitive disturbances; rare metabolic bone diseases with special reference to osteogenesis imperfecta and fibrodysplasia ossificans progressiva (FOP) and bone loss in children. Participant of many conferences and patient meetings on FOP in US and Europe. Participant Longitudinal Study of Osteoporosis in Women (GLOW) (2005-2016). Since 2010 co-founder, co-worker Salt Osteoporosis Study; an open randomised pragmatic trial, studying a primary care structured identification and treatment program in women aged 65 years or older of 240 GP-practices. Co-founder of ICCBH (International Conference on Children's Bone Health); first chair in Maastricht, The Netherlands (1999) and member of the scientific committee of the second and following conferences in Sheffield 2002 and Sorrento 2005, Montreal 2007, Cambridge 2009, Rotterdam 2013, Salzburg 2015 and Wurzburg 2017. Author/Co-author of more than 200 scientific publications of which more than 165 are listed in "Pubmed."

*Session Moderator

SPEAKER BIOGRAPHIES

Dan Perrien, Ph.D.

Assistant Professor of Medicine
Vanderbilt University Medical Center

Dr. Dan Perrien is an Assistant Professor of Medicine in the Vanderbilt Center for Bone Biology at Vanderbilt University Medical Center where his research program currently focuses on understanding the role of innate immunity in FOP flares and a collaboration with Drs. Charles Hong and Corey Hopkins to develop small molecule ALK inhibitors to treat FOP and other ALK-driven diseases. Much of his 15+ years of experience in bone biology has focused on bone repair, disuse, and the roles of Inhibins and Activins in bone turnover and osteoporosis. After receiving his Ph.D. in Physiology and Biophysics from the University of Arkansas for Medical Sciences, he joined an orthopaedic-focused biotech company in Tennessee. There, his responsibilities focused on preclinical and clinical development of two rhPDGF-BB based products to enhance bone repair, Augment™ and Augment Injectable™ bone grafts, which are now approved for clinical use in the U.S. and/or other countries. In 2008, he joined the Vanderbilt Center for Bone Biology where his work returned to mechanotransduction, imaging, and the TGFβ-superfamily. Approximately 5 years ago, he began his collaboration with Dr. Charles Hong to advance preclinical development of ALK inhibitors for FOP. Shortly thereafter he expanded his work in FOP to include understanding the role of macrophages, innate immunity, and inflammation in the initiation and propagation of FOP flares.

Robert Pignolo, M.D., Ph.D.

Kogod Professor and Chair, Geriatric Medicine & Gerontology
Mayo Clinic

Dr. Pignolo has worked on basic science, translational and clinical aspects of FOP for over 16 years, first at the University of Pennsylvania Center for Research on FOP & Related Disorders in Philadelphia, and now at the Mayo Clinic in Rochester, Minnesota. A major focus of his research is drug discovery and repurposing of drugs for the treatment of FOP. He is currently the principal investigator of the palovarotene interventional trial at the Mayo Clinic.

Xiaobing Qian, M.D., Ph.D.

Executive Director, Early Clinical Development and Experimental Sciences
Regeneron Pharmaceuticals, Inc.

Dr. Xiaobing Qian is Executive Director Early Clinical Development and Experimental Sciences at Regeneron Pharmaceuticals, based in Tarrytown, NY. She obtained her medical training in Beijing, China at Beijing Medical University (now Peking University Health Science Center), and her Ph.D. from University of Illinois Chicago Medical Center.

Dr. Qian has more than 19 years of experience in drug discovery and development across a broad spectrum of therapeutic areas including hematology, lipid metabolism, cardiovascular diseases, oncology, autoimmune and inflammatory diseases, pain, and muscle and bone diseases. She has led preclinical and clinical research and development teams to advance small molecules, biologics, and gene therapy drug candidates from target validation through early clinical development in common and rare diseases.

Dr. Qian has been with Regeneron since 2007. In addition to her role as a Medical Director, she also led a Translational Medicine Strategy Group, an internal "think tank," to research scientific and medical rationale and clinical research strategy to accelerate the development of innovative drug candidates created at Regeneron Laboratories into transformative medicines to meet high unmet need in patients. Her current work focuses on clinical development of an Activin A mAb for fibrodysplasia ossificans progressiva (FOP). Dr. Qian serves as a member of the FOP Connection Registry Medical Advisory Board.

SPEAKER BIOGRAPHIES

Roberto Ravazzolo, M.D.*

Professor of Medical Genetics
University of Genova and G. Gaslini Institute

Roberto is Professor of Medical Genetics at the University of Genova, Italy and Director of the Medical Genetics Unit at the G. Gaslini Children Hospital in Genoa. His main research interest is studying the molecular defects that cause rare genetic disorders and their pathogenic mechanisms to possibly design new therapeutic approaches.

Academic degrees

- University of Genova, Medical School, 1971, Medicine Doctor
- University of Genova, Medical School, 1973, Specialization in Haematology
- University of Genova, Medical School, 1977, Specialization in Internal Medicine

Professional activity

- Professor of Medical Genetics, University of Genova, Medical School, 1988 to present
- Director - Medical Genetics Unit, G. Gaslini Institute, Genova,1998 to present
- Director - Department of Pediatrics, University of Genova, 2009 to 2012
- Visiting Scientist, University of Texas M.D. Anderson Cancer Center, Houston, Texas, U.S.A., from 1989 to 1990
- Professor of Biology, University of Genova, Medical School, 1987 to 1988
- Researcher, University of Genova, Medical School, 1981 to 1987
- Contract for research and teaching, University of Genova, Medical School, 1974 to 1981
- Research fellowship, University of Genova, Medical School, 1973 to 1974
- Research contract, University of Genova, Medical School, 1971 to 1972

Ton Schoenmaker, B.Sc.

Research Technician
Academical Centre of Dentistry (ACTA)

Ton Schoenmaker is research technician at the department of periodontology at the Academical Centre of Dentistry (ACTA) in Amsterdam. For the past several years he has been working with Teun de Vries doing research on osteoclasts focusing on the molecular biology within this research. In the past two years Ton has been collaborating with the Dutch expert center in FOP. As a newcomer, he felt the engagement of the FOP research community at patient days in The Netherlands and during an FOP international scientist workshop held in The Netherlands that was organized in December 2015 by the Dutch FOP research team. Ton recently started his Ph.D. project on the role of osteoclasts in FOP.

The periodontology department became involved in the FOP research because of their expertise in osteoclast biology, but also because of their experience with working with periodontal ligament fibroblasts (PLF), one of the few cell types that can be isolated from FOP patients without severe side effects. They recently developed a cell culturing system using these PLF cells to study osteoclast formation and function. The first results using this system were recently published in *Bone* (*Bone*, 2017 Jul 10. (17) 30233-8).

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SPEAKER BIOGRAPHIES

Chris Scott, M.D.*

Associate Professor and Head of Paediatric Rheumatology
University of Cape Town

Dr. Scott is Associate Professor and head of Paediatric Rheumatology at Red Cross War Memorial Children's Hospital in Cape Town. He also works in Paediatric Nephrology and General Paediatrics. His research seeks to understand key issues in and improve care for children with rheumatic and musculoskeletal disease. He has initiated the first training program in Paediatric Rheumatology at University of Cape Town, training fellows from South Africa and other African countries. He has participated in multiple international research collaborations. He is the South African coordinator for PRINTO, the Paediatric Rheumatology International Trials Organization and participates in a number clinical trials in children with rheumatic diseases. He also collaborates with researchers in South America and Europe.

His research areas include:

- Fibrodysplasia ossificans progressiva (FOP)
- Social justice and access to care for patients with rare disease in developing countries
- Paediatric Rheumatology Education in developing countries
- SLE in Africa
- Juvenile Idiopathic Arhthritis
- Rheumatic Manifestations of HIV
- Tuberculous Arthritis
- Takayasus Arteritis

Adam Sherman, B.S., M.B.A.

Director of Research Development & Partnerships
International FOP Association

Adam started at the IFOPA in March 2017 as the Research Development & Partnerships Director. He is a seasoned biopharmaceutical professional with over 22 years of experience in drug development and leading research collaborations for rare diseases. Adam worked in the Personalized Genetic Health business unit at Genzyme for 15 years overseeing a portfolio of rare diseases therapeutics. Prior to joining the IFOPA, Adam worked at Biogen as the Executive Director of Program Leadership and Management. During his tenure at Biogen, Adam was responsible for leading the lifecycle management strategy for two hemophilia drug products. He developed and executed the largest-ever humanitarian aid program for hemophilia, with a commitment to delivering up to 1 billion IUs (market value, $2 billion) of hemophilia factor to the developing world. Adam also worked at Ironwood Pharmaceuticals where he served as a R&D program leader for the linaclotide franchise. Adam has an B.S. in biochemistry and a M.B.A from Boston University.

Eileen M. Shore, Ph.D.*

Professor, Departments of Orthopaedic Surgery and Genetics
Cali/Weldon Professor of FOP Research
Co-Director, Center for FOP and Related Disorders
Perelman School of Medicine at the University of Pennsylvania

Dr. Eileen M. Shore is a Professor at the Perelman School of Medicine at the University of Pennsylvania in the Departments of Orthopaedic Surgery and Genetics. She received a B.Sc. from the University of Notre Dame, a M.A. degree in Biology from Indiana University, and her Ph.D. in Cell and Molecular Biology from the University of Pennsylvania. Following postdoctoral studies in cell biology at the Fox Chase Cancer Center, she returned to the University of Pennsylvania and now holds the inaugural Cali/Weldon endowed chair and, with Dr. Fred Kaplan, is the co-Director of the Center for Research in FOP and Related Disorders.

In order to identify treatment targets and strategies for fibrodysplasia ossificans progressiva (FOP), Dr. Shore's research investigates multiple aspects of the cellular and molecular mechanisms that promote the dysregulated bone formation that causes heterotopic ossification in FOP.

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SPEAKER BIOGRAPHIES

Laura Silvestri, Ph.D.

Tenured Scientist
San Raffaele Scientific Institute, Milan, Italy

Laura Silvestri has long-term expertise in the characterization of molecular mechanisms responsible of the pathogenesis of human genetic disorders, as hemochromatosis, beta-thalassemia and Iron Refractory Iron Deficiency Anemia (IRIDA). In particular, she is interested in the signaling pathways regulating hepcidin, the hormone that controls body iron levels. Among them, BMP-SMAD is the dominant signaling pathway. Her studies are focused on the characterization of proteins involved in this pathway, as the BMP-coreceptor hemojuvelin and the hepatocyte transmembrane serine-protease 6 (TMPRSS6). Laura's recent interests are novel hepcidin regulators as the immunophilin FKBP12, and their role in IRIDA and FOP, two entirely different disorders sharing a common pathogenic mechanism that is the inappropriate activation of the BMP-SMAD pathway. Recently, in collaboration with Renata Bocciardi and Roberto Ravazzolo Laura reported the characterization of a FOP patient also affected by IRIDA (De Falco et al., Hum Mut 2010). They demonstrated that the mutation of the BMP-receptor ALK2R258S responsible of FOP and impaired in FKBP12 binding, contributes to hepcidin upregulation in the liver and accounts for the IRIDA phenotype in the presence of TMPRSS6 haploinsufficiency (Pagani et al., Blood 2017). These results demonstrate a previously unsuspected role for FKBP12 as a modulator of the hepatic BMP-receptor ALK2.

Junya Toguchida, M.D., Ph.D.

Professor
Center for iPS Cell Research and Application, Kyoto University

1975-1981	Undergraduate, Faculty of Medicine, Kyoto University
1985-1989	Graduate, Graduate School of Medicine, Kyoto University
1989-1991	Research fellow, Massachusetts Eye & Ear Infirmary, Harvard Medical School
1995-1998	Associate Professor, Department of Artificial Organs, Research Institute for Biomedical Engineering, Kyoto University
1998-2003	Associate Professor, Department of Tissue Engineering, Institute for Frontier Medical Sciences, Kyoto University
2003-2016	Professor, Department of Tissue Engineering, Institute for Frontier Medical Sciences, Kyoto University
2010-	Professor & Deputy Director, Department of Cell Growth & Differentiation, Center for iPS Cell Research and Application, Kyoto University
2016-	Professor, Department of Tissue Regeneration, Institute for Frontier Life and Medical Sciences, Kyoto University
2016-	Professor, Institute for Advancement of Clinical and Translational Science, Kyoto University Hospital, Kyoto University

SPEAKER BIOGRAPHIES

Jim Triffitt, B.Sc. (Hons), Ph.D.*

Professor Emeritus
Botnar Research Centre, NDORMS, University of Oxford

Jim Triffitt graduated from the University of Liverpool in 1961 and gained his Ph.D. there in 1964. Subsequently he joined Professor W.F. Neuman at the University of Rochester, New York to work on bone mineral dynamics. In 1969, he joined the Oxford MRC Bone-Seeking Isotopes Research Laboratory to expand his interests in defining the organic matrix of bone. A move to the Nuffield Orthopedic Centre in 1974 enabled closer collaboration with Dr. Roger Smith, who promoted research interests in rare bone conditions. In particular, ectopic ossification became central and the involvement of the hypothetical molecule proposed by Urist in 1965 to cause bone induction. In 1979, he joined Professor Urist in California at UCLA for a two-year sabbatical to work on bone morphogenesis and isolation of the active morphogenetic principle. In 1992, he was appointed director of the MRC Bone Research Laboratory at the Nuffield Orthopedic Centre and set up the University of Oxford FOP Research Fund. His FOP Research Group was central in discovery of the causative gene for FOP as part of an international consortium. In collaborations with Dr. Alex Bullock and scientists at the SGC, the structure of the resultant protein was discovered and the structural basis of FOP proven.

Stelios Tsigkos, M.Sc. M.D. Ph.D.

Scientific Officer, Orphan Medicines Office,
European Medicines Agency

Stelios completed his MD and PhD at the University of Athens, published research in the field of endothelial signalling and angiogenesis and worked as a clinician prior to joining the EMA. Stelios also completed an MSc in European Policy and Management in the University of London. Since joining the Orphan Medicines Office in 2009, Stelios has gained experience in assessing applications and developed an interest for integrating clinical, scientific and regulatory concepts. Towards this end, he has also lead several publications in the field of orphan medicines regulation in Europe.

Simona Vallara

Board Member
FOP Italia Onlus

Simona became a member of FOP Italia after her younger daughter, Isabella, was diagnosed with FOP in 2009, when she was 12 years old. She has served the Italian organization contributing to the Board of Directors activity and, together with her husband Massimo and her daughter Eleonora, promoting a series of fundraising efforts and media opportunities for FOP awareness. Simona got a degree in Foreign Languages and Philosophy at the University of Parma, and a Master in Professional Counseling in 2010. She is currently teaching English in public high schools, and practicing counseling activity with teachers and students.

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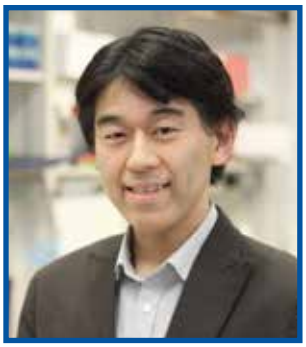
SPEAKER BIOGRAPHIES



Toshifumi Yokota, Ph.D.

Associate Professor
University of Alberta

Dr. Toshifumi Yokota, Ph.D. is Associate Professor and Muscular Dystrophy Canada Research Chair at the University of Alberta. His overarching research goal is to find cures for neuromuscular and musculoskeletal diseases. His initial training was in the molecular characterization involved in muscular dystrophy at the University of Tokyo and the National Center of Neurology and Psychiatry Japan. Subsequent to doctoral studies, he moved to the Imperial College London, UK, and then Children's National Medical Center in Washington DC for postdoctoral training. He demonstrated the first successful systemic treatment of dystrophic mouse and dog models with exon skipping, a novel therapy using DNA-like molecules. In support of his research program, he currently holds a number of research grants from funding agencies including IFOPA, CIHR, NIH, and Muscular Dystrophy Canada. His current projects focus on the antisense therapy and exon skipping therapy for various mutations and types of neuromuscular and musculoskeletal diseases.

Paul Yu, M.D., Ph.D.*

Associate Professor of Medicine
Harvard Medical School and Brigham and Women's Hospital

Dr. Yu's laboratory studies the function of bone morphogenetic protein (BMP) signaling in vascular development, disease and remodeling. BMPs provide critical signals for pattern formation and organogenesis, regulate tissue remodeling postnatally, and contribute to cardiac, pulmonary vascular and bone metabolic diseases. Dr. Yu's lab has developed novel small molecule reagents for modulating BMP signaling, and have employed these reagents to explore physiologic and pathophysiologic functions of BMP signaling. The lab has also examined the consequences of dysregulated BMP signaling in models of human disease, focusing on heterotopic ossification, pulmonary arterial hypertension, and vascular calcification. A major goal of the lab's work is to discern how BMP/TGF-β signaling achieves spatio-temporal and functional specificity, and how this pathway modulates tissue-specific consequences of inflammation and injury. Dr. Yu's lab's work interfaces with vascular and progenitor cell biology, signal transduction and pharmacology.

Dr. Paul Yu is Associate Professor of Medicine at Harvard Medical School and Physician in Cardiovascular Medicine at Brigham and Women's Hospital. Dr. Yu completed his AB in Philosophy and a BS in Biological Sciences at Stanford University, M.D. and Ph.D. (Immunology) degrees at Duke University, followed by Internal Medicine residency training at the University of California, San Francisco, and clinical fellowship in Cardiovascular Disease at Massachusetts General Hospital. After a postdoctoral fellowship in the laboratory of Dr. Kenneth Bloch, Dr. Yu joined the faculty at Massachusetts General Hospital and Harvard Medical School in 2006, and joined the faculty in Cardiology at Brigham and Women's Hospital in 2011. Dr. Yu is board certified in Internal Medicine and Cardiovascular Medicine.

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