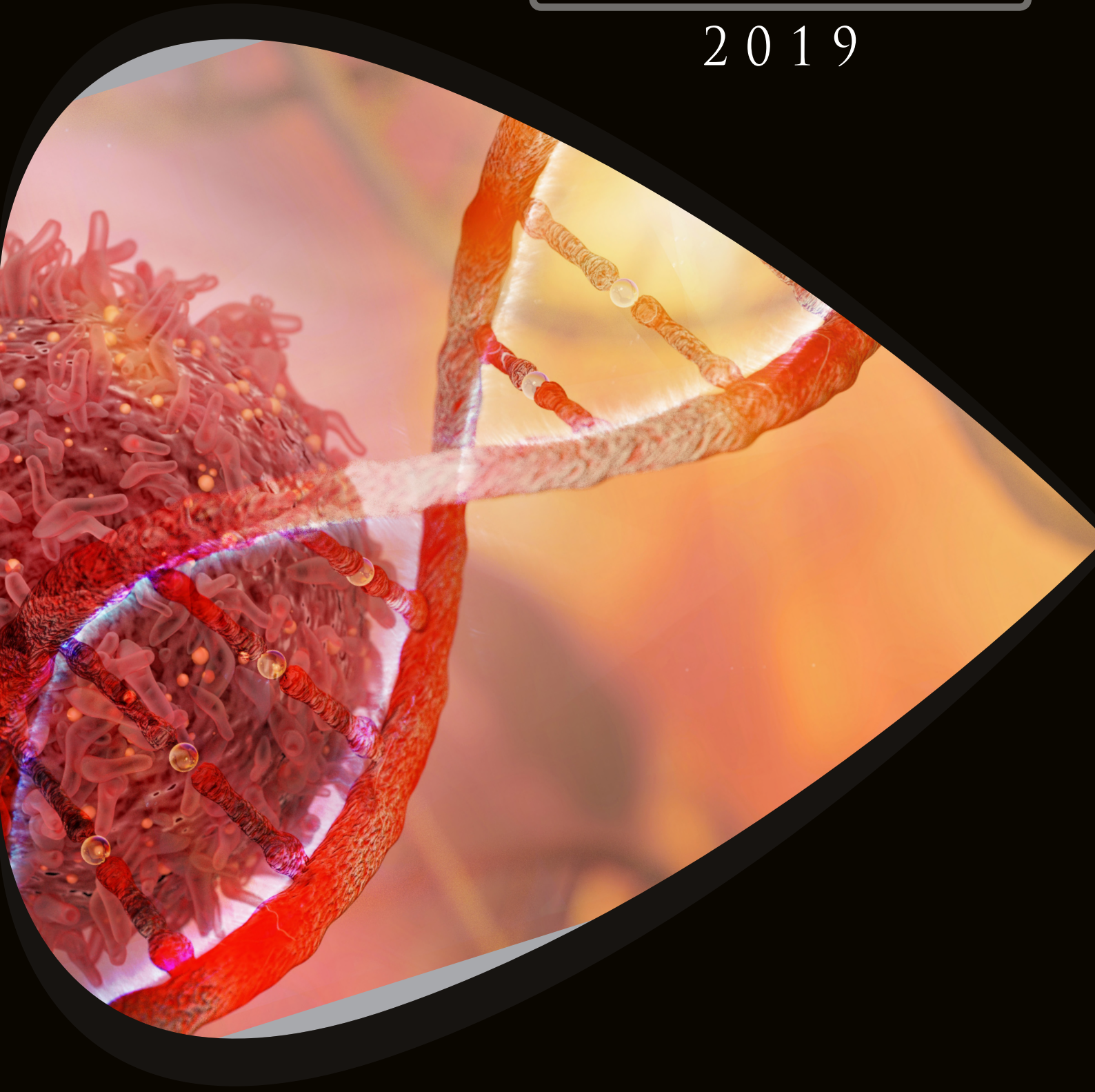
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TENTATIVE PROGRAM

2019



10th Annual Congress on

RARE DISEASES AND ORPHAN DRUGS

September 26-27, 2019 Charlottesville | USA

10th Annual Congress on

RARE DISEASES AND ORPHAN DRUGS

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Program @ Glance

Day 1 September 26, 2019	
Opening Ceremony	
Plenary & Keynote Speeches (09:00-11:30)	
Networking and Refreshments Break	
Group Photo	
Speaker Session I (11:30-13:00)	Different types of Rare Diseases | Clinical Research and Public Awareness | Mystery Diagnosis of Rare Diseases
	Panel Discussion
Lunch Break	
Speaker Session II (13:00-16:00)	Challenges in Rare Diseases Treatment | Rare Infectious Diseases and Immune Deficiencies | Rare Diseases in Cancer
	Panel Discussion
Networking and Refreshments Break	
Speaker Session III (16:00-18:00)	Rare Diseases in Aging | Orphan Drugs- development trends and strategies | Orphan Drugs and Ethical Issues
	Panel Discussion
Day 1 concludes…	
Day 2 September 27, 2019	
Opening Ceremony	
Plenary & Keynote Speeches (09:00-11:30)	
Networking and Refreshments Break	
Speaker Session I (11:30-13:00)	Clinical Research on Orphan Drugs | Orphan Drugs and Ethical Issues | Future Hereditary of Rare Diseases and Orphan Drugs | Entrepreneurs Investment Meet
	Panel Discussion
Lunch Break	
Speaker Session II (13:00-16:00)	Different types of Rare Diseases | Mystery Diagnosis of Rare Diseases | Patient organizations and their role in drug development or clinical research
	Panel Discussion
Networking and Refreshments Break	
Speaker Session III (16:00-18:00)	Poster Presentations
	Best Poster Award Distribution
Day 2 concludes…	



A patient at the table: How partnership with patients improves research and enhances service delivery

Alastair Kent, Genetic Alliance, UK



Measuring the impact of diagnosis and treatment of rare diseases

Alba Ancochea, EURORDIS, Spain



Targeting familial Alzheimer's disease

Michael S. Wolfe, University of Kansas, USA



Consumer Directed Precision Health - Convergence of Multi- omics, Environment, Life style and Behaviors

Praduman Jain, Vibrent Health Inc., USA



Speeding up access to medicines for patients with unmet medical need: Integrating evidence and regulatory pathways

Stella Blackburn, QuintilesIMS, UK

Past Keynote Speakers



Pediatric Rare Disease Enrollment Case Study in Latin America

Sara Tylosky, Farmacon, USA



Lifting the burden of Rare Disease by providing access to next generation sequencing

Romina Ortiz, Rare Genomics Institute, USA

Past Workshop's



Helping patients cope with, and recover from the effects of living with a rare disease: A patient's perspective

Mark Landiak, Corporate Dynamics, Inc. USA



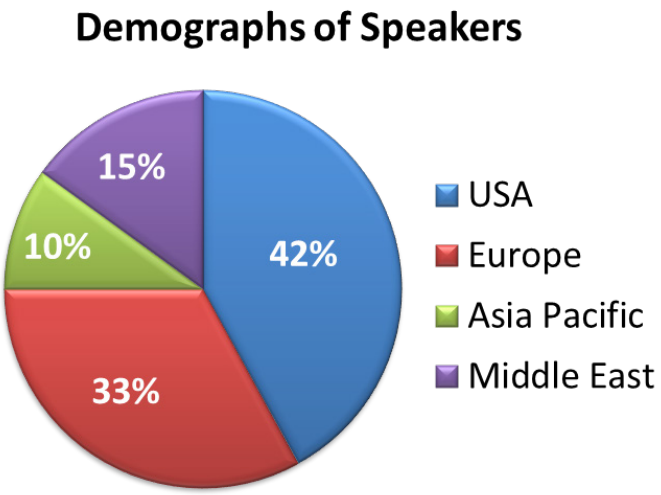
Overview of rare disease funding at NIH

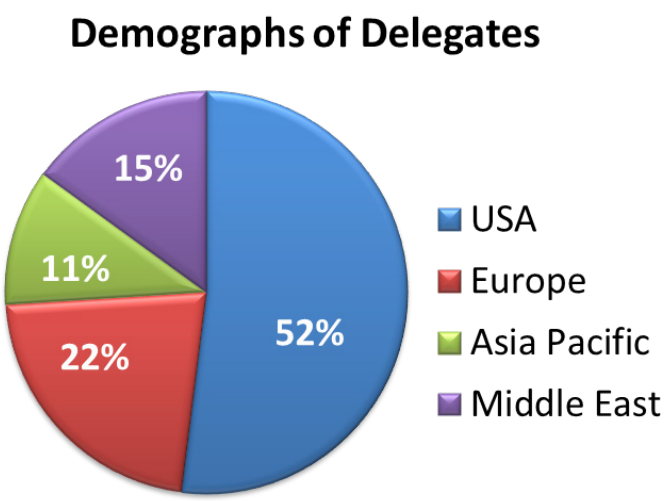
Jason Wan, National Institutes of Health, USA

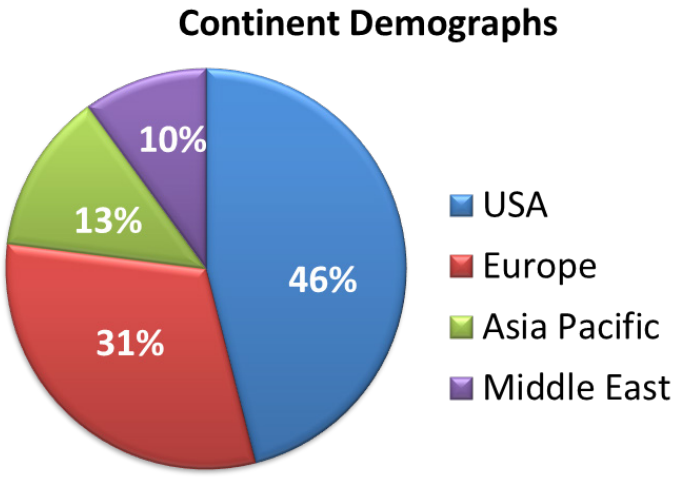


How to educate others about your rare disease

Dana Mauro, National Ataxia Foundation, USA







Our conference is surrounded with Doctors, Deans, Professors, Students, Young researchers, Health Practitioners, Relevant Association and Societies, Business professionals all over the globe, from which most of them are decision makers.

Illustrated in Figure 1, 2 and 3 are the recent Demographs for Speakers, Delegates and attendees from the Continents.

Rare Diseases and Orphan Drugs, past Speakers & Delegates

Abdulaziz Aldawood, King Saud Bin Abdulaziz University, Saudi Arabia

Alan B. Moy, The John Paul II Medical Research Institute and Cellular Engineering Technologies, USA

Alan Gilstrap, Akcea Therapeutics, USA

Alastair Kent, Genetic Alliance, UK

Alba Ancochea, EURORDIS, Spain

Alice Abdel Aleem, Weill Cornell Medical College, Qatar

Amrik Sahota, Rutgers University, USA

Anne Marie Finley, Biotech Policy Group LLC, USA

Annemieke Aartsma-Rus, Leiden University Medical Center, The Netherlands

April Weir Hauptman, InClin, USA

Ashwani K Singal, University of Alabama at Birmingham, USA

Aya Narita, Tottori University Hospital, Japan

Charles Du Mond, InClin, USA

Courtney Smith, Colpitts Clinical, USA

Dana Mauro, National Ataxia Foundation, USA

Daniel Cohen, Pharnext , France

Danilo A Tagle, National Institutes of Health, USA

David Dongliang Ge, Apostle Inc. , USA

Deanna Laurain, InClin, USA

Diego-Abelardo Alvarez-Hernandez, Anahuac University, Mexico

Dung-Fang Lee, The University of Texas Health Science Center at Houston, USA

Duygu Kuyuncu Irmak, INC Research, Turkey

E. Dewsnup, Epilepsy Association of Utah, USA

Fahd Al Mulla, Kuwait University, Kuwait

Fernando Ferrer, Multinational Partnerships LLC, USA

Gail Adinamis, GlobalCare Clinical Trials, LLC, USA

Gayathri Balasubramanian, Focus Scientific Research CenterPhamax, India

George Faurot, InClin, USA

Gianluca Colella, Rizzoli Orthopaedic Institute, Italy

Godwin Oligbu, St Georges Hospital London, UK

Harsha K Rajasimha, George Mason University, USA

Irene Tan, Temple School of Medicine, USA

Isabelle Windheuser, University Hospital Bonn, Germany

Jacques P Tremblay, Universite Laval, Canada

Jacques P. Tremblay, Department of Molecular Medecine, Université Laval, Québec

Janel Long-Boyle, University of California San Francisco, USA

Jason Wan, National Institutes of Health, USA

Jianmeng Chen, Food and Drug Administration, USA

John A Mauro, National Ataxia Foundation, USA

John Leaman, Selecta Biosciences, USA

Jong Wook Chang, Samsung Medical Center, South Korea

Karen S. Ho, Lineagen, Inc, USA

Karren Williams, Akcea Therapeutics, USA

Katarína Šimeková, University Hospital in Martin, Slovak Republic

Kei Kishimoto, Selecta Biosciences, USA

Kim Frieze, InClin, USA

Larissa Wester, University Hospital Bonn, Germany

Laura Sunderlin, Beazley, USA

Laxminarayan Bhat, Reviva Pharmaceuticals Inc, USA

Laxminarayan Bhat, Reviva Pharmaceuticals, Inc, USA

Lei He, Food and Drug Administration, USA

Leonardo Cano, Universidad Católica Santiago de Guayaquil, Ecuador

Lisa Baumbach- Reardon, Translational Genomics Research Institute, USA

Maite A. Castro, Universidad Austral de Chile, CHILE

Manoj Krishnan, Duke-NUS, Singapore

Maria Shkrob, Elsevier, USA

Marise Abdou, Abo El-Rish Children's Hospital, Cairo, Egypt

Mark Landiak, Patient Advocate, Foundation for Sarcoidosis Research, USA

Megan O'Boyle, Phelan-McDermid Syndrome Foundation, USA

Michael S Wolfe, University of Kansas, USA

Mingli Jiao, Harbin Medical University, China

Moamen Al Zoubi, Advocate Illinois Masonic Medical Center, USA

Moji C. Adeyeye, Roosevelt University, USA

Nadia Ameen, Yale University School of Medicine, USA

Nasir Ali Afsar, Alfaisal University College of Medicine, KSA

Ndiaye Mady, Faculty of Medicine of Thiès, Nigeria

Patrick J Tighe, University of Nottingham, U.K

Philippe Jouvet, Sainte-Justine Hospital University of Montreal, Canada

Prasanth Puthanveetil, Roosevelt University College of Pharmacy, USA

Ramune Sepetiene, Lithuanian University of Health Sciences, Lithuania

Rashmi Gopal-Srivastava, NCATS, NIH, USA

Rob W J Collin, Radboud University Medical Center, Netherlands

Róbert Rosoľanka, University Hospital in Martin, Slovak Republic

Romina Ortiz, Rare Genomics Institute, USA

Ryan Clift, InClin, USA

Samuel Ayoola Abati, lagos university, Nigeria

Sara Tylosky, Farmacon, USA

Serge Braun, Scientific Director, AFMTelethon, France

Shin'ichi TAKEDA, National Institute of Neuroscience, Japan

Shipra Agrawal, The Research Institute at Nationwide Childrens Hospital, USA

Shmuel Prints, Clalit Health Service, Israel

Stefano Giacomini, Rizzoli Orthopedic Institute, Italy

Stella Blackburn, QuintilesIMS, UK

Stephen P. Arneric, Critical Path Institute, USA

Stephen Shrewsbury, Fortuna Fix, USA

Stephen Smolinski, Selecta Biosciences, USA

Sujatha Kannan, Johns Hopkins University School of Medicine, USA

Tatjana Michel, University Hospital Tuebingen, Germany

Thomas C Chen, Keck School of Medicine of USC, USA

Timothy Coté, Coté Orphan, USA

Tony Zbeidy, Orphan-Europe, France

Wei Zheng, National Institutes of Health, USA

Xavier Paoli, Pharnext, France

Xiaolan Zhang, Sarepta Therapeutics, USA

Yingjun Xie, The Third Affiliated Hospital of Guangzhou Medical University, China

Yoko Sato, National Defense Medical College, Japan

Yolande van Bever, Erasmus Medical Centre, The Netherlands

Yong Moon Choi, Bio-Pharm Solutions Co., Ltd, South Korea

Yunzhao Ren, Food and Drug Administration, USA

Yusuf Hovsep Eken, Elkerliek ziekenhuis, Netherland



WHAT YOU CAN EXPECT























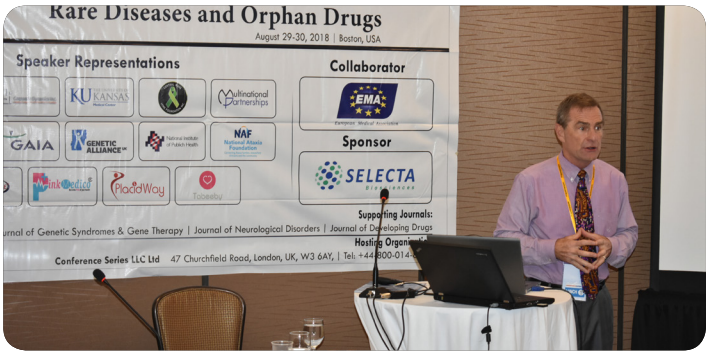


Glimpses of Rare Diseases Conference



















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