

May 23-25, 2023

Gaylord National Harbor, Washington, DC



# THE WORLD'S MOST IMPORTANT ORPHAN DRUG AND RARE DISEASE EVENT





Featuring:



# STATS & FEATURES



300+
SPEAKERS



50+
COUNTRIES



3000+ 1-2-1 MEETINGS



2000+
ATTENDEES



100+
EXHIBITORS



16 STREAMS OF CONTENT



PRE-CONFERENCI WORKSHOPS + SEMINARS



# **OUR STORY**

The World Orphan Drug Congress USA is back for its 13th edition! We are excited to be returning to Gaylord National Harbor, just outside Washington, DC, May 23-25, 2023.

Since its inception in 2010, The World Orphan Drug Congress has solidified its position as the largest rare disease and orphan drug conference, globally. Over 3 days, you will have the opportunity to hear from 300+ speakers across our 16 themes of content, engage in networking opportunities and customize your experience at the congress.

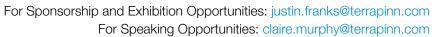
This conference attracts the entire rare disease ecosystem – breaking down silos and fostering collaboration to help rare disease patients. The leading orphan drug pharmaceutical and biotech companies, government and regulatory authorities, patient advocacy groups, payers, investors and solution providers rely on the congress to convene and brainstorm ways to advance orphan drug development and improve access to life-saving therapies.

Get ready for the most comprehensive program and inclusive gathering of rare disease stakeholders!

In 2023, over 2000+ attendees, from 50+ countries, will gather in Oxon Hill, MD for the next World Orphan Drug Congress USA.

We can't wait to see you May 23-25, 2023!









# PAST SPEAKER Shannon Resetich Global Franchise Head, Rare Diseases, Sanofi

# **OUR WORLD-CLASS CONFERENCE FEATURES THE FOLLOWING THEMES:**



**PATIENT DATA** 



NEXT GENERATION THERAPIES



**PAYERS** 



CLINICAL DEVELOPMENT AND REGULATORY



COMMERCIAL



RARE DISEASE ADVOCACY
WORLD



GLOBAL MARKET & PATIENT ACCESS



PRICING & REIMBURSEMENT



**PITCH & PARTNER** 



ADVANCED THERAPIES – MANUFACTURING



ADVANCED THERAPIES – CLINICAL DEVELOPMENT



RARE ONCOLOGY



ADVANCED THERAPIES – COMMERCIALIZATION



DIGITAL HEALTH &
ARTIFICIAL INTELLIGENCE



DIAGNOSIS



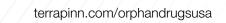
DISCOVERY







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# HALL OF FAME SPEAKERS



Janet Woodcock
Acting Commissioner, Food and
Drug Administration (FDA)



Shannon Resetich Global Franchise Head, Rare Diseases, Sanofi Genzyme



Suneet Varma
Global President of Rare Disease,
Pfizer



**Dara Richardson-Heron**Chief Patient Officer, **Pfizer Inc** 



Emil Kakkis
President and Chief Executive
Officer, Ultragenyx
Pharmaceutical



**Jeremy Levin**Chairman and Chief Executive
Officer, **Ovid Therapeutics** 



Samarth Kulkarni Chief Executive Officer, CRISPR Therapeutics



Violeta Stoyanova-Beninska Chair of Committee for Orphan Medicinal Products, Medicines Evaluation Board, European Medicines Agency



Evert Jan van Lente Chair, MEDEV, Director EU-Affairs, AOK-Bundesverband



Bobby Gaspar
Chief Executive Officer, Orchard
Therapeutics



Maryam Matar
Founder & Chairperson, UAE
Genetic Diseases Association



Avinash Shanbhag
Director, Nationwide Health
Information Network Division,
US Department of Health and
Human Services



Sandy Macrae
President And Chief Executive
Officer, Sangamo Therapeutics



Sara Nochur Chief Regulatory Officer, Regulatory Affairs, Alnylam Pharmaceuticals



Peter Saltonstall Chief Executive Officer, NORD



Yann Le Cam
Chief Executive Officer, EURORDIS

- Bare Diseases Europe



Andrew Obenshain
Chief Executive Officer, bluebird



Troyen Brennan
Executive Vice President and Chief
Medical Officer, CVS Health



Jessica Scott
Head of R&D Patient Engagement
Officer, Takeda



Yukiko Nishimura President, ASrid Japan



Peter Marks
Director, Center for Biologics
Evaluation and Research (CBER),
Food and Drug Administration
(FDA)



Steven Peskin
Associate Clinical Professor of
Medicine, Rutgers RWJ Medical
School, Executive Medical
Director Population Health and
Transformation, Horizon Blue
Cross Blue Shield - New Jersey



**Derek Adams**Chief Technology & Manufacturing
Officer, **bluebird bio** 



**Debra Miller**Founder and CEO, **CureDuchenne** 



Nancy Mendelson Chief Medical Officer, Complex Health Solutions, UnitedHealthcare



James Mullen
Chairman, President, Chief Executive
Officer, Editas Medicine



John Crowley Chairman & CEO, Amicus Therapeutics



Rachelle Jacques
Chief Executive Officer, Enzyvant



David Lennon
President, Novartis Gene
Therapies



Michael Boyle
President and Chief Executive
Officer, Cystic Fibrosis
Foundation



Amanda Moore
Chief Executive Officer, Angelman
Syndrome Foundation



Geoff MacKay
Chief Executive Officer, AVROBIO



Durhane Wong-Rieger
President And Chief Executive
Officer, Canadian Organization
For Rare Disorders



**Avril Daly**Vice Chair EURORDIS, CEO, **Retina**International



Larry Bressler Head of Value & Market Access, Chiesi Global Rare Diseases



Vikram Karnani
Executive Vice President,
President, International, Horizon
Therapeutics



Phillip Brooks
Program Director, NCATS, National
Institutes of Health (NIH)



Fanny Sie
One Roche, Head of Artificial
Intelligence and Digital Health,
Roche



Luc Boileau Président-directeur general, INESSS



Richa Poddar
Chief Commercial Officer, Agios
Pharmaceuticals



Heidi Bjornson-Pennell
Patient Engagement
Strategist, Chan Zuckerberg
Initiative



Alba Ancochea Díaz

Chief Executive Officer, FEDER



Paul Aliu Head Global Governance Office, Novartis Chief Medical Officer (CMO), Novartis



Assistant Professor, Division of

Medical Ethics, NYU Grossman

School of Medicine

Annie Kennedy

Annie Kennedy Chief of Policy and Advocacy, EveryLife Foundation for Rare Diseases



Mark Trusheim Strategic Director, MIT NEWDIGS



Emily McGinnis Chief Patient Officer and Head of Government Affairs, Taysha Gene Therapies



Amy Nicole Nayar
Vice President of U.S. Patient
Advocacy & Government Affairs,
Novartis Gene Therapies



Anna Bucsics
Project Advisor, Mechanism of
Coordinated Access to orphan
medicinal products (MoCA)



# **TOPIC AREAS**



**CLINICAL DEVELOPMENT &** REGULATORY



RARE DISEASE ADVOCACY WORLD



**ADVANCED THERAPIES** CLINICAL



**PRICING &** REIMBURSEMENT



AI & DIGITAL HEALTH



PITCH AND PARTNER

# **WHO ATTENDS**

### Pharma, biotechs

- VP Clinical Development
- Chief Medical Officer
- Chief Scientific Officer
- Regulatory Affairs
- President, Head of Rare Diseases
- Decentralized Clinical Trials (DCT)
- Patient Voice

### Pharma, biotechs

- Chief Patient Officer
- VP Patient Advocacy
- Medical Affairs
- Patient Engagement

### **Patient Advocacy Groups**

- Founder, CEO or President
- VP Regulatory Affairs
- Vice President, Community Engagement
- VP Communications

### Pharma, biotechs

- VP Gene Therapy
- Chief Medical Officer
- Chief Scientific Officer
- Global Head of Gene Therapy
- Heads of Research and Development
- Chief Executive Officer
- Chief Regulatory Officer

### Pharma, biotechs

- Chief Executive Officer
- VP, Head of Market Access
- VP, Head of Pricing and Reimbursement
- VP of Health Economics/HEOR
- VP of HTA
- Head of Value Demonstration
- VP, Evidence and Data
- Payers (public and private)
- Government & Regulatory agencies

# Pharma, biotechs

- Chief Data Officer
- Chief Technology Officer
- Chief Operating Officer
- VP, Analytics
- Head of Innovation
- Head of Digital

# Hospitals and healthcare centers

### **Payers**

### Pharma, biotechs • CFO

- Presidents
- Chief Business Officer
- VP Business Development
- VP External Innovation
- VP R&D

### **Venture Capital Firms**

**Grant Agencies (Public and Private)** 

Licensing pharma

### TOPIC AREAS:

- Patient centric clinical development
- Clinical trial design
- Real world evidence in clinical development
- Expanded access pograms / Managed Access Programs
- Access programs

- Patient Data
- Patient Registries & Patient Reported Outcomes (PROs)
- Evolving role of patient groups in R&D
- Genetic testing & diagnosis

Setting up patient groups

- Advocacy & Policy
- Industry collaboration

- Gene therapy development
- Cell therapy development
- Translational science and path to clinical
- Regulation

- Advanced therapies pricing & reimbursement
- Real World Evidence
- Health Technology Assessment
- Value Based Assessment
- Next generation pricing and innovative pricing models
- Al in drug discovery
- Patient identification
- Data analytics
- Data collection through wearables and applications
- Advanced therapies investment
- Risk assessment
- Partnering and co-development opportunities
- Funding
- Accelerating orphan drug development
- Successful case studies

# WHO SHOULD SPONSOR:

- Contract Research Organizations (CROs)
- Contract Development and Manufacturing Organizations (CDMOs)
- Clinical Trials Services
- Home Clinical Trials
- Patient Recruitment & Identification
- Regulatory Consulting

- Pharma & biotechs
- Research Institutions
- Patient Registries
- Patient Engagement Platforms
- Genetic Testing providers
- Genomic Sequencing Platforms
- Diagnostics

- Advanced therapies pharma & biotechs
- Gene Editing biotechs
- Contract Research Organizations (CROs)
- Clinical trial design

- PRO consultancies and PRO technology providers
- Value communication organizations
- Pricing & Reimbursement consulting firms
- HEOR service providers
- Patient registries and database providers
- Artificial Intelligence platforms
- Patient identification solutions
- Machine learning
- Data analytics
- Wearable technology Digital Health Apps
- Patient registries

- Advanced therapies investment

Partnering and co-development

Risk assessment

opportunities

**Funders** 



# **TOPIC AREAS**



**COMMERCIAL** 



**DIAGNOSIS** 



**ADVANCED THERAPIES MANUFACTURING &** 



**GLOBAL MARKET ACCESS** 



**DISCOVERY** 



**RARE ONCOLOGY** 

# WHO ATTENDS

### Pharma, biotechs

- Chief Commercial Officer
- VP Commercial Operations
- VP of Marketing
- VP Medical Affairs

### Pharma, biotechs

- Presidents & Heads of Patient Diagnosis Programs
- R&D Strategic Alliance

### **Rare Disease advocacy organizations**

Newborn Screening

### Pharma, biotechs

- Chief Operating Officer
- Chief Manufacturing & Technology Officer
- VP Technical Operations
- VP of CMC
- VP Manufacturing
- VP of Process Development
- VP of Quality Control

### Pharma, biotechs

- VP Market Access
- Pricing and Reimbursement
- Chief Commercial Officer
- International Business

### Regulators

### Government

- Ministry of Health
- Policy makers

# Pharma, biotechs

- Heads of Discovery
- VP Clinical Development
- Chief Medical Officer
- Chief Scientific Officer
- Regulatory Affairs
- President, Head of Rare Diseases

# Pharma, biotechs

- VP Cell Therapy
- Head of Oncology
- Head of Immunotherapy
- Chief Medical Officer

# TOPIC AREAS:

- Business models
- Forecasting and Epidemiology
- Global expansion and internationalization
- Business development

- Genetic counselling
- Industry partnerships
- Genomics
- Newborn Screening
- Access & Reimbursement of testing
- Process development
- Outsourcing
- Viral vector development
- Manufacturing efficiency and capacity
- Analytical development
- **Quality Control**

- Market entry strategies
- Stakeholder collaboration for market
- Real World Evidence
- Improving access
- International regulation

- Discovery platforms
- Artificial Intelligence & Machine Learning
- Small molecule development
- Scientific innovations
- Collaborations

- Diagnosis
- Biomarker R&D
- CAR-T development
- Advocacy and patient voice
- Clinical development and commercialization

# WHO SHOULD SPONSOR:

- Specialty Pharmacy
- Logistics, Supply Chain, 3PL
- Strategic Consulting
- Real World Evidence
- Forecasting and Epidemiology

Marketing, Communications Agency

- Genetic testing companies Genetic counselling consulting
- Genomics companies
- Newborn screening providers
- Process development
- Outsourcing
- Viral vector development
- Manufacturing efficiency and capacity
- Analytical development

- Market entry strategies
- Stakeholder collaboration for market
- Real World Evidence
- Improving access
- International regulation

- Drug discovery companies
- Artificial Intelligence and Machine Learning applications
- Predictive analytics platforms
- Contract Research Organizations (CROs)
- Immunoncology pharma and biotechs
- Contract Manufacturing Organizations
- Contract Research Organizations (CROs)
- Genomic/DNA sequencing



# **PAYERS SEMINAR**

On this seminar, payers from around the world will discuss approaches and strategies to improve pricing & reimbursement in rare diseases, including innovative pricing schemes and optimization of value-based assessments.



# **NEXT GEN THERAPIES SEMINAR**

Learn about novel pipelines, approaches and candidates on the Next Generation Therapies Seminar, where someday these technologies and therapies could be the common place to treat rare diseases

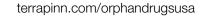


# **PATIENT DATA SEMINAR**

When developing therapies for rare and ultra-rare diseases the value of patient data is immensurable. Though patients and their families are usually willing to share their data to advance research being their individual causes, issues with data privacy, ownership, consent and handling are still a big hurdle impeding the progress of utilizing data to identify patients, shorten the time for an accurate diagnosis, build disease knowledge, expedite R&D, and enhance access to available therapies.



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# **ATTENDEES INCLUDE**





































































































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# 250+ PARTICIPATING PATIENT ADVOCACY **GROUPS:**

A.T. Childrens Project ADNP Kids Research Foundation Adult Polyglucosan Body Disease Research Foundation Advocacy & Awareness for Immune Disorders Association Alagille Syndrome Alliance Alport Syndrome Foundation Americas Health Foundation Angelman Syndrome Foundation Aplastic Anemia and M.D.S. International Foundation Inc Autism Science Foundation Axis Advocacy Barth Syndrome Foundation Batten Disease Support and Research Association Ben's Friends **Bow Foundation** Bridge the Gap -SYNGAP Canadian Organization for Rare Caregiver Action Network Cauda Equina Foundation CDH International Children's Tumor Foundation Chinese Organization for Rare Disorders Circadian Sleep Disorders Network Cooley's Anemia Foundation Costello Syndrome Family Network **CRMO** Foundation CSNK2A1 Foundation Cure Blau Syndrome Foundation Cure VCP Disease CureDuchenne Cures Within Reach CureSPG50

Curing Retinal Blindness Foundation

Cushing Support and Research

Cystic Fibrosis Foundation

Dreamsickle Kids Foundation

Foundation

Dup15q Alliance

FCS Foundation

Einstok Born

EURORDIS

America

E.C.D. Global Alliance

FamilieSCN2A Foundation

Fibromuscular Dysplasia Society of

Fibrous Dysplasia Foundation

Fighting For Kaiden Fondation

FOXG1 Research Foundation FSH Society Inc Glut1 Deficiency Foundation Hairy Cell Leukemia Foundation Helping Hands for GAND Hereditary Angioedema Association Highway of Hope Hopeful Science Progressiva Association International Prader-Willi Syndrome Organization International Waldenstrom's Macroglobulinemia Foundation Jett Foundation Jonah's Just Begun KLS Foundation Little Hercules Foundation Little Miss Hannah Foundation Liv4TheCure Loulou Foundation Allliance Mast Cell Hope Mila's Miracle Foundation Miracles For Mito MLD Foundation Muscular Dystrophy Association Muscular Dystrophy UK Diseases - Bulgaria National Ataxia Foundation National Fragile X Foundation National M.P.S. Society National Niemann Pick Disease Foundation Inc Neuromuscular Disease Foundation Noonan Syndrome Foundation NORD Osteogensis Imperfecta Foundation Patient Airlift Services Perthes Kids Foundation Progeria Research Foundation

Foundation

Foundation for Angelman Syndrome Therapeutics Foundation For Prader Willi Research Foundation for Sarcoidosis Research Friedreich's Ataxia Research Alliance International Fibrodysplasia Ossificans Jersey Lymphangiomatosis & Gorham's Disease Malta National Alliance for Rare Diseases National Alliance of People with Rare Phelan-McDermid Syndrome Foundation Project Alive PTEN Hamartoma Tumor Syndrome

Rare Bone Disease Alliance Rare Kids Network Reccurent Respiratory Papillomatosis Foundation Reflex Sympathetic Dystrophy Syndrome Association RSDSA Rubinstein Taybi Syndrome Childrens Foundation Sara's Cure Sarcoidosis of Long Island Sickle Cell 101 Sickle cell intervention U.K. Sickle Cell Thalassemia Patients Network Sickled Not Broken Foundation Simons Foundation Clinical Research Associates SMA Europe Snyder Robinson Foundation Team Sanfilippo Foundation Texas Rare Alliance The Aarskog Foundation The American Porphyria Foundation The Chandler Project, Inc. The Jansens Foundation The Myositis Association The Sickle Cell Association of New The Sturge-Weber Foundation The Yellow Brick Road Project Transient Global Amnesia Project Tuberous Sclerosis Alliance U.S. Food and Drug Administration (FDA) United Leukodystrophy Foundation United Spinal Association We CARE Journey Malaysia Wylder Nation Foundation **KBG** Foundation Sickle Cell Community Consortium Beyond The Diagnosis **BPAN Warriors** 

CureCMT4J Adult Sickle Cell Foundation of Nevada -Bridging the Gap **Uplifting Athletes** EveryLife Foundation for Rare Diseases Narcolepsy Network Metro DC EDS & HSD Support Group Kleine-Levin Syndrome Foundation Foundation Ichthyosis and Related Skin The Sickle Cell Foundation of Tennessee Canadian MPS Society Aidan Jack Seeger Foundation Associacao Brasileira De Paramiloidose Immune Deficiency Foundation Canadian Pituitary Patient Network Acromegaly Community Vasculitis Foundation

Maltepe University/Medical

The Cute Syndrome Foundation

Asociación Gaucher de México

MCAS Hope Germany

South Carolina Rare Action Network

Vancouver Acromegaly Support Group

Faculty

Global Genes

RACC-UK













Present new technology and ideas WITH a 20min breakout presentation







# **SPONSORSHIP & EXHIBITION PACKAGES**

Benefits	Title	Diamond	Platinum	Gold	Silver	Exhibitor
Keynote plenary	1 x 20min in plenary	1 x 20min in plenary				
20 min Presentation or 40 min Panel	1 x 20min in track		1 x 20min in track OR 1 x 40min Panel	1 x 20min in track OR 1 x 40min Panel		
Roundtable		1 x 1 hour Roundtable			1 x 1 hour Roundtable	
White Paper Release through	Eblast, Blog, Newsletter, Social Media	Eblast, Blog, Newsletter, Social Media	Eblast, Blog, Newsletter, Social Media	Eblast, Blog, Newsletter, Social Media		
Branding	Lanyards	Wifi	Track Sponsorship			
Staff Passes	10	9	7	6	5	3
Guest Passes (clients)	7	5	4	3	2	
1-2-1 Meetings	7	5	3			
Stand size	400	200	200	200	100	100
Price (USD)	60,000	45,000	30,000	20,000	12,500	8,500

# **SPONSORSHIP OPPORTUNITIES**



# PRE-CONFERENCE WORKSHOP \$30,000 USD

Pre-Conference workshop to be held on the afternoon of May 23rd. Topics to be chosen by sponsor



# MAIN COCKTAIL RECEPTION \$30,000+ USD

Main reception following Day 1. Sponsor responsible for cost of food, beverage, & venue.



# MOBILE APP \$30,000 USD

Exclusive to one sponsor. On-site SMS messaging and branding rights to networking ann



# REGISTRATION \$25,000 USD

Includes branded desks, directional signage, floor clings, and listed as exclusive sponsor on agenda and floorplan.



# WELCOME PARTY RECEPTION \$20,000+ USD

Evening before Day 1. Sponsor responsible for cost of food, beverage, & venue.



# LANYARD \$30,000+ USD

Exclusive to one sponsor. Sponsor responsible for cost of lanyard production. To be placed on racks at registration for all attendees.



# NETWORKING LOUNGE \$20,000+ USD

Exclusive to one sponsor. Branding in the expohall. Sponsor responsible for furnishing space.



# WIFI \$15,000 USD

Exclusive to one sponsor. Custom network name and password.



# HEADSHOT STUDIO \$25,000+ USD

Exclusive to one sponsor. Sponsor responsible for cost of photographer and associated fees.



# TRACK SPONSOR \$10,000 USD

Exclusive to one sponsor per track. Branding on podium, signage, agenda, floorplan. Moderator from your company.



# **TOTE BAGS \$10,000 USD**

Exclusive to one sponsor. Sponsor responsible for cost of production of totes and shipping.



# PPE BRANDING \$10,000 USD

Branded masks, hand sanitizer, hand sanitizer stations. Included on floor clings promoting social distancing. Sponsor responsible for cost of merchandise and shipping.



# HOTEL KEYCARDS \$5,000+ USD

Exclusive to one sponsor. Sponsor responsible for cost of production and hotel service.



# NETWORKING BREAK \$5,000 USD

30 sec ad shown in breakout rooms and app.



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# **2022 SPONSORS**

TITLE



# **PLATINUM**









# **DIAMOND**





# **GOLD**









































# **SILVER**

























# **EXHIBITORS**



























The support, kindness, courtesy and interest shown by WODC Team in our company's drug development program for orphan disease glioblastoma, to aid us to secure funding to run registration trials.

Chief Executive Officer, Tactical Therapeutics Inc



# **START-UP ZONE & POSTER SESSIONS**THE FUTURE OF ORPHAN DRUGS STARTS HERE

# Start-Up Zone

The World Orphan Drug Congress USA will provide a platform for start-ups working on the future of orphan drugs, while connecting them to the world's most influential companies, investors, and media.

Investors come to the World Orphan Drug Congress start-up zone to find their next unicorn. Global media come to look for their next story. Companies come to look for partnerships and acquisitions.

As part of our start-up zone, you will be given a space on the expo floor to showcase your solutions.

And the best part? It is at zero cost to you! Click <u>here</u> to apply for the start-up zone, or email **victoria.wagner@terrapinn.com**.

# **Poster Sessions**

Call for poster abstracts! This year, the World Orphan Drug Congress USA is accepting abstracts for poster sessions. If you are an academic, researcher, or patient advocacy organization in the rare disease and orphan drug space, you can apply to present a poster on the expo floor. You will receive a free pass to attend the conference and receive a space in the expo hall to display your poster.

To learn more, please click <u>here</u> for additional instructions, submission criteria, and deadlines, or email **victoria.wagner@terrapinn.com**.





# **BRAND AWARENESS**

Thousands of rare disease professionals, from around the world, come to the World Orphan Drug Congress, giving you the platform to tell your story on a global scale.



# **FUNDING**

Meet VCs looking for early stage opportunities as well as companies looking for partnerships and acquisitions.



# **NETWORKING**

Your networking experience starts as soon as download our app — before the conference even begins, you can chat with potential leads, and arrange meetings. At the conference, you'll make some of your most valuable connections as they see your stand and demonstrations in-person.



For Sponsorship and Exhibition Opportunities: justin.franks@terrapinn.com For Speaking Opportunities: claire.murphy@terrapinn.com





# **CONTACT US**



**CONFERENCE PRODUCTION** 

Claire Murphy

T +1 646 619 1784

E claire.murphy@terrapinn.com



**SPONSORSHIP & EXHIBITION SALES** 

Justin Franks

T +1 914 819 3506

E justin.franks@terrapinn.com



**MARKETING OPPORTUNITIES** 

Taylor Post

T +1 646 619 1785

E taylor.post@terrapinn.com