

BioTechX

8-10 November 2022
Basel Congress Center, Switzerland

BioTechX

Data. AI. Precision. Innovation.
For Pharma, Healthcare & Partners



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Bi@DataWORLD congress
PharmaA **GenomicsLIVE**
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A 4 in 1 world-class conference that covers BioData World, Genomics Live, Cheminformatics Live & PharmaI. We're excited to announce there are 300+ world-class speakers now confirmed including Bayer, Novartis, Novo Nordisk, Sano Genetics, AstraZeneca and more.

To support the voice of patients at events, Terrapinn has generously agreed to give Rare Disease Patient Advocates a space at the event to engage industry leaders and open dialog between all players.

Patient Advocates will be coming to the event from around the world, and unlike members of Industry, most do not have a travel budget. This gives Industry the unique opportunity to direct support the Patient Voice by sponsoring the Patient Advocacy section of BioTechX.



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FOR IMMEDIATE RELEASE: BioTechX 2022 Congress Implements New Patient Advocacy Initiative

BioData 2022 Congress Implements New Patient Advocacy Initiative

London, United Kingdom / Basel, Switzerland – Tuesday, March 22, 2022 – Patient advocates and rare disease nonprofits are overjoyed that the medical conference organizer, Terrapinn, has created a new platform to include patient voices.

“This November, BioData World Congress returns to Basel along with three co-located events. We are so excited to announce that this year BioData World Congress will take place alongside Genomics Live, PharmAI, and Cheminformatics Live. This is Europe's largest conference covering big data in pharmaceutical development and healthcare and will bring together thousands of industry leaders” announces Terrapinn on the company's call for speakers.

Dawn Ireland attended her first Terrapinn event at the World Orphan Drug Congress in 2017 in Washington DC. “I was so impressed that this company was so inclusive of patients and patient advocates. Most industry events forget that patients are the consumers and should be the focus of all events. Right away, I knew that I would be attending a lot of Terrapinn organized events,” said Ireland, who is a patient advocate and president of CDH International, a global charity for Congenital Diaphragmatic Hernia patient support and research.

Ireland began speaking, chairing, and representing patients at Terrapinn's BioData conference in Basel, Switzerland and World Evidence, Pricing and Access (EPA) Congress in Amsterdam. In March of 2021, she secured a block of time for patient advocates at the EPA's virtual event by tapping into her network of other advocates and her relationship with the Terrapinn team.

In November of 2021, the BioData Congress was back to an in-person event and had a great attendance but there was a lack of patient advocates. She went to Chris Shanks, head of the EPA event and admin of the BioData, and asked for another block for patient advocates. Shanks agreed and gave Ireland 3 hours.

Ireland took the project to the Worldwide Rare Advocacy Partnership (WRAP), a new collaboration she co-founded with 4 fellow patient advocates. By the time the next meeting with Terrapinn was held, there were 15 well-known, well-respected patient advocates who were signed up to roll up their sleeves and bring Patient Advocacy to Terrapinn events in Europe.

“Sharing the rare patient voice at an international medical conference is so important to our patient groups. Patients and patient families want to be so much more than a number on a laboratory slide or a name on a registry. They want to be a real live human representation, not just their disease,” says Caryl Harris, co-founding partner at WRAP and Executive Director of Avery's Hope, a patient assistance organization for the rare pediatric GI patient community.

Shanks responded by giving Ireland the WRAP team 3 days instead of 3 hours, and Terrapinn became the first company to officially incorporate an equal presence of Patient Advocacy at a medical industry event.

“Usually, medical conferences will give advocates and charities a discounted vendor booth, a few opportunities to speak at round tables or panels but Terrapinn has always shown Patient Advocacy as much respect as they show big Pharma and other industry players. They treat us as equals and that's how every medical conference should be. We are so grateful to them for leading the way in this important cause,” says Ireland.

“Being able to share the human side to medical data gives researchers and medical teams an opportunity to see disorders and disease from a fully human perspective,” says Harris.

“I'm thrilled to finally see a conference organizer include the patient advocate voice on such a large scale. It's long overdue and perhaps the most important voice to hear. Thank you, Terrapinn,” says Terri Ellsworth, KOL Rare Disease Patient Advocate and the 3rd of 5 WRAP Co-Founding Partners.

Ireland and her partners at WRAP are looking for more Patient Advocacy leaders to speak on BioData, as well as corporate sponsors to cover their costs to attend the event. You can reach out to her at dawn.ireland@cdhi.org to participate.

BioData will take place on November 8-10th at the Basel Conference Center in Switzerland. Learn more about the event at: <https://www.terrapinn.com/conference/biodata/index.stm>

Contact:

Dawn Ireland at dawn.ireland@cdhi.org.

Ironically, the upcoming BioTech X Conference to be held in Basel, Switzerland on November 8-10, 2022 uses the subheading “Data. AI. Precision Innovation for Pharma, Healthcare and Partners. To look at the conference agenda, it would appear that “partners” include scientists, researchers, physicians, geneticists and other number crunching members of this exclusive group. For the first time in its history, the organizers of the conference were finally convinced that rare patients and rare disease advocates were a very necessary part of the conference. It might be cliché at this point, but without the rare voice, rare disease patients are nothing but blood stains on a slide without looking at the whole human being. Yes, rare disease patients are human beings deserving of all of the same health care as healthy human beings. However, because this is the first year of including patients and advocates, there will be no stipend, no travel or lodging assistance. Rare patients and rare disease advocates are often without the financial means to attend this type of conference. It is at this particular conference that Rare Disease Advocates from around the globe and rare disease patients have the opportunity to educate and empower the research world with real world human data in the hopes of moving the needle towards health equity for all. Therefore, we are requesting a grant to help four speakers who are active members of the rare disease community to attend this important event.

The barriers to health equity go well beyond race and gender. The rare, ultra-rare and undiagnosed community of patients are marginalized even prior to diagnosis if there is ever one. Access to standards of care, such as whole genome sequencing, access to genetic counselors, access to medications and treatments and the high cost of out-of-pocket and insurance denied expenses keep patients and patient families from receiving the care that they need and deserve. Our group of speakers will address each of these issues at the conference along with access to registries, clinical trials, Safe Step Act trials and tribulations, access to travel to treatments, trials, and second and third opinions. Our being at the conference will both help and advance health equity for rare disease patients. We have been given three days to educate, enlighten and enrich the data driven medical and research community. This will make a difference.

The organizers of the conference have given rare disease advocates three full days to speak, round table and “partner” with medical researchers. Agenda topics include: Patient Advocates in Collaboration with Researchers, Patient Created Natural History Registries, roundtables on Standards of Care, the High Cost of Living Rare and so much more. Sharing our real-life data, experiences and insights will help researchers to anticipate, adapt and influence health equity in the immediate future and well beyond. Hearing from patients about their barriers to clinical trials, to second opinions and most importantly to diagnosis and care will bring attention to real human beings and not a number in a research laboratory.

Our entire intention is to humanize the rare disease experience for the medical researchers. By educating this group on that side of the research, we expect to see more partnerships, better funding for rare disease patients to fully participate in their health care. Grant funding for travel and lodging in Basel would allow at least four well seasoned speakers to represent the rare disease community. While the disease groups they represent may be all different, the end goal is the same. Speakers would include Dawn Ireland, Caryl Harris, Carie Chester and Terri Ellsworth.

Rare patient voices represent all human beings regardless of race, gender or social situation. If patients are much more than a blood stain on a lab slide, then we must participate fully when looking at research, including clinical trials, treatment, and most importantly, standards of care. Without rare voices working in complete collaboration and partnership with the medical research community, there will never be health equity. As rare disease advocates, we plan on changing that.

- Caryl Harris



CARYL HARRIS

CO-FOUNDER OF AVERY'S HOPE
RARE GASTROINTESTINAL DISEASES PATIENT ADVOCATE

WORLDWIDE RARE ADVOCACY PARTNER



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Current Speakers for this section are:

- Dr. Wendy Chung – Columbia University CARES for Kids, DHREAMS, KidsFirst Database
- Dr. Dick Tibboel – Erasmus MC, ICU
- Dr. Augusto Zani – Zani Lab, University of Toronto
- Dawn Ireland – Founder of CDH International, Patient Registry creator, global Patient Advocate working in 84 countries
- Luke Rosen – Founder of KIFIA.ORG, a nonprofit organization working to rapidly discover treatment for KIFIA Associated Neurological Disorder. Senior Vice President, Accelerated Development & Community Engagement at Ovid Therapeutics.
- Caryl Harris – Co-Founder & Executive Director, Avery's Hope, Patient Ambassador for Illumina, Former member of Rare Advocacy Movement
- Terri Ellsworth – Professional Rare Disease KOL, Patient Advocate Thought Leader, Consultant, Public Speaker
- Sean Gordon – “After being diagnosed with an adult-onset rare disease, I have founded www.rarefundingteam.com bringing together communications professionals and rare disease organizations on a pro bono basis. I bring over two decades of experience in sales & marketing of technology products.”
- Dr. Neena Nizer – Executive Director of The Jansen's Foundation. Patient and mother to two superheroes with Jansen's Metaphyseal Chondrodysplasia. Working on a cure for JMC.
- Taylor Kane – Community Engagement Manager at AllStripes, Founder and Executive Director at Remember The Girls, Rare disease speaker, advocate, consultant, and author
- David Rose – Business Development at Rare Revolution Magazine. Ultra-Rare Disease Patient Speaker. Trustee for Mitrofanoff Support.
- Meghan Rauen LCMHCA/NCC – Founder and President, Global Gastroschisis Foundation. “ I have extensive education and research in the medical communications, counseling, trauma, religion and medicine, patient communications, and bioethics/medical ethics.”
- Eden Lord – Founder & CEO at The Dash Alliance, Creator of the first virtual rare disease events, “The Rare Fair”, “24 Hours of Rare” & “Rare 72”, a collaborative model for rare disease solutions. Rare Disease Mom & Patient
- Jeff Lord – Chief Technology Officer (CTO) My City Med, rare disease dad
- Monica Weldon – Son 1 of 6 diagnosed globally in 2012 with SYNGAP1, rare disease advocate, Founder, Biotech Investor @syngap1_Fnd VAMO contributor @pharmaboardroom
- Onno Faber – TedEx speaker, scientist, CEO Rarebase, Founder of AllStripes, entrepreneur, keynote speaker, author, patient advocate, angel investor
- Jason Miller – Patient Registry Administrator, CDH International
- Carolyn Dumond – Associate Director, Global Patient Advocacy at Illumina
- Carie Chester – Lead Manager, Exam Operations & Services Lead Manager, Exam Operations & Services AICPA
- Thomas Hach - Executive Director, Patient Engagement Cardiovascular, Renal & Metabolism, Novartis
- Bradley Pryde - COO, One Three Biotech



DAWN IRELAND

PRESIDENT AND FOUNDER, CDH INTERNATIONAL
CONGENITAL DIAPHRAGMATIC HERNIA ADVOCATE
LONG COVID PATIENT ADVOCATE

WORLDWIDE RARE ADVOCACY PARTNER



TERRI ELLSWORTH

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Level:	Cost:	Includes:
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Diamond Sponsorship	\$50,000	<ul style="list-style-type: none"> Extra-large logo on signage at the event Listed as sponsor on 10 presentations Listed as Patient Advocacy Sponsor 3 panel seats Vendor table Two 20-minute presentations

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TERMS & CONDITIONS:

Before you sponsor the event, the following are the terms and conditions that your brand has to consider:

1. The sponsorship and donation amount should be given to the organization on or before 30 days before the event.
2. If you are chosen as a sponsor, your contract will be terminated only on the last day of the event.
3. All sponsors, vendors and speakers must follow guidelines set by Terrapinn.
4. As a sponsor, you are free to promote your products, brand, and other related offers. However, make sure that it is relevant to the theme of the event and please do not hang out any merchandise or set up any displays not in alignment with your sponsorship level.

If you abide by the terms and conditions, please fill the form on the next page and submit it to us on or before the day of the event.

Please complete the online registration form at [www.https://cdhi.org/biotechx/](https://cdhi.org/biotechx/). You may also print and complete the form below. You will receive a confirmation once payment is received.

Please return the completed form and your logo via email to sponsor@cdhi.org

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End Of Proposal

THANK YOU

We appreciate your time and consideration and look forward to working with you to give patients a voice at this important event.



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