Delivering Outstanding Rare Care: Q&A Released with Rare Disease Revolutioner, L. Kerecuk, Ahead of Orphan Drugs Event

Rare disease expert speaks to SMI Group in the run-up to her featured address on the 100K Genome

LONDON, UNITED KINGDOM, August 15, 2017 /EINPresswire.com/ -- SMi Group are thrilled to release an interview with Larissa Kerecuk, ahead of her presentation on Developing the 1st Rare Disease Centre for Children in the World at the 7th annual conference on Orphan Drugs and Rare Diseases this Autumn.

With a wealth of experience and devotion to leading the development of the first pediatric Rare Disease Centre in the World, providing a diagnosis and personalised approach to many yet undiagnosed children, Larissa is a rare disease renowned revolutioner known for promoting a holistic approach.

As the founder and coordinator of the Autosomal Recessive Polycystic Kidney Disease Rare Disease Group in the UK, Larissa and her team have established international collaborations with the US and Europe, which has also developed the Human Factors Course to improve patient safety. With patient safety as her driving force, Larissa became NIHR Clinical Specialty Lead for Paediatrics in the West Midlands to work towards her vision of research become an integral part of everyday NHS care. Focusing on collaboration, the presentation will offer attendees with guidance into the importance of research and collaboration for progression in the rare disease field.

> it is vital to collaborate to develop novel treatments for rare diseases. Funding should be prioritised to researchers who are willing to collaborate with clinicians and patients"
>
> *Larissa Kerecuk*

Understanding the major challenges of rare diseases faced by people affected by rare disease will be a key focus, as will hearing about patient history – a patient speaks and the development of the 100K Genome, will be just some of the highlights in her talk.

"The perspective that I am bringing to the conference is from the clinicians and patients within the NHS with all the challenges that families affected by rare diseases must deal with on a daily basis: from getting a

diagnosis to being able to have some form of treatment for the patient and the effect the rare disease has on the whole family”

In the run up to the event, SMi Group caught up with Larissa to discuss her view of the orphan drug landscape and how she sees it evolving in the upcoming years.
“...This is both an exciting and challenging time for the orphan drugs industry: there are so many different possible treatment avenues becoming apparent with the genomic era of knowledge but challenging in terms of fast-changing global regulations and markets. There is huge growth potential as the new genomic knowledge is explored and built upon. Improvement is required from all stakeholders to work more collaboratively to achieve therapeutic benefits to patients as quickly and safely as possible…”

The full interview is available to read in the event download centre.

Running alongside the conference will an exclusive pre-conference workshop held on Tuesday 17th October 2017.
WORKSHOP: Rare Diseases Challenges and Opportunities
Workshop Leaders: Larissa Kerecuk, Rare Disease Lead, Consultant Paediatric Nephrologist, Birmingham Children’s Hospital & Janet Tuberville-Greenlay, Roald Dah; Rare Disease Transitition Sister, Birmingham Children’s Hospital

For those wanting to attend, there is currently an early bird offer available; book by 31st August 2017 to save £200 off the conference price. Register at www.orphandrugs.co.uk/EIN

For sponsorship packages: Contact Alia Malick +44 (0) 207 827 6168 or e-mail amalick@smi-online.co.uk.
For delegate enquiries: Contact Sean Vaghela on +44 (0) 20 7827 6744 or email saghela@smi-online.co.uk
For media enquiries, contact Kyra Williams on +44 (0) 20 7827 6012 or email kwilliams@smi-online.co.uk

Orphan Drugs and Rare Diseases UK
18th – 19th October 2017
London, UK
www.orphandrugs.co.uk/EIN
Contact e-mail: kwilliams@smi-online.co.uk
Contact tel: +44 (0) 207 827 6012
#smiorphandrugs

---- END ----
About SMi Group: Established since 1993, the SMi Group is a global event-production company that specializes in Business-to-Business Conferences, Workshops, Masterclasses and online Communities. We create and deliver events in the Defence, Security, Energy, Utilities, Finance and Pharmaceutical industries. We pride ourselves on having access to the world’s most forward thinking opinion leaders and visionaries, allowing us to bring our communities together to Learn, Engage, Share and Network. More information can be found at http://www.smi-online.co.uk

Kyra Williams
SMi Group Ltd
+44 (0)20 7827 6012
email us here