

Monday, June 22 2020

Doctorate student joins international panel of experts.



Image caption: Sondra Butterworth with Alan Thomas, Founder of Ataxia and Me. Ataxia is a rare neurological disease. Sondra also volunteers for Ataxia and Me.

A PhD student at the University of Chester has joined an international panel of experts, who are working to improve the lives of people living with a rare disease across Europe.

Sondra Butterworth is based in Llandrillo, near Corwen in North Wales, and trained as a general nurse in Cardiff. She is proud to be raising awareness about rare diseases in Wales. (Sondra is also the sister of the first black rugby player to play for Wales – Glenn Webbe’s book, written with Geraint Thomas - *The Gloves Are Off* - is currently shortlisted for Rugby Book of the Year in *The Telegraph’s Sports Book Awards 2020*.) With a professional background in education, mental health and social care, she is studying for her PhD through the University’s Faculty of Health and Social Care.

Her PhD research has been based on quality of life and social support in adults with rare genetic skin conditions. Currently, most rare disease research focuses on the physical aspect of conditions, rather than looking at the importance of a holistic biopsychosocial approach (the interconnection between biology, psychology, and socio-environmental factors) to support and care. Sondra also recently presented a paper about her research - ‘Stories are not just for bedtime’ - at the 10th European Conference on Rare Diseases and Orphan Products.

As a result of her studies at Chester, she has built a reputation in her field, which has also culminated in an appointment onto the Board of Genetic Alliance UK. Now she has been invited to sit on an international Rare2030 Panel of Experts, which has been set up to progress policies for those living with a rare disease.

According to its website, Rare 2030 is a foresight study that gathers the input of a large group of patients, practitioners and key opinion leaders to propose policy recommendations that will lead to improved policy and a better future for people living with a rare disease in Europe. The project will end in a presentation to Parliament at the end of 2020 with recommendations on the most critical areas needing sound policy.

Sondra said: “I am delighted to be able to take up this position on such a prestigious panel. Rare2030 is about the future of rare diseases and the quality of life for those who have them. Patients are the experts in their own experience and it’s vital that they have a voice. I believe that my research is perfectly timed for me to be part of this vital, international discussion, and that this role will give me an opportunity to contribute to the wellbeing of the rare disease community and under-represented groups.”

Sondra’s PhD supervisor, Associate Professor Andrew Mitchell from the Faculty of Health and Social Care, said: “This is an excellent opportunity for Sondra to share her knowledge and expertise while shaping policy in the area. I believe that her dedication and enthusiasm will allow a voice in this critical and much-needed area of health care. I know that her PhD thesis on quality of life and biopsychosocial aspects will contribute and add to the rare diseases community.”

Her joint PhD supervisor, Professor Elizabeth Mason-Whitehead, who is Head of the Chester Medical School, said: “Sondra’s research is rooted in her professional practice and a fine example of how many Chester PhD students enhance the knowledge base of their subject, informing and developing policy and practice. “Equally, as principal supervisor, Andrew demonstrates how Chester PhD students are both nurtured and stretched by excellent supervisors, committed to supporting students throughout the whole of their PhD journey.”

Sondra has also received information and support from the University of Chester’s Venture Programme, run by Careers and Employability, to help her with her new social enterprise – RareQoL – which will be launching in July. Sondra is delighted that brother Glenn will be the RareQoL ambassador.

Sondra added: “I intend to focus on Quality of Life issues as part of my role on the Rare2030 panel: it seems so appropriate and timely given lockdown conditions at the moment, and the effect that this is having on those living with rare diseases and their families.”

ENDS

Contact:

Jayne Dodgson
Director of Corporate Communications
+44 (0)1244 511450
07841 250221

Nan Pickering



University of Chester

Communications Officer
+44 (0)1244 513335
07917 591437

Alex Williams
Senior Communications Officer
+44 (0)1244 511706
07768 671436

www.chester.ac.uk