

Cambridge International Rare Disease Summit

Monday 23 October 2017

Calling all Rare Disease patient groups and patients - come and share your patient journey!

As part of our Rare Disease Summit, we will be creating patient journey posters and stories. We will be circulating these amongst Pharma, clinicians and trusts.



Kay Parkinson

CEO, Cambridge Rare Disease Network (CRDN) Founder/Director of Alström Syndrome Europe, Founder of Alström Syndrome UK

Do they know your symptoms?

Do they know what aspects of your condition need treatment?

Are there opportunities for drug matching or clinical trials that they and you are aware of?

Could your patient journey poster make a difference, like Kay's poster?

What will **you need** on your poster?

- Logo or image
- Causes of the Condition
- Symptoms and Treatments
- Impact of the Condition
- Hopes and Aspirations for the Future



Full details of our poster guidelines and prizes can be found on our [website](#)

When do we need your poster by?

Please submit your patient journey poster by 11 Sept 2017

Where will my poster be displayed?

On our poster gallery at #CRDN2017, at the summit during networking breaks, in the delegates' pack and in our booklet produced post event. The winning five poster authors, will also get the opportunity to pitch to the 200+ audience at the summit.

I'm interested where do I **send** my poster?

Send your poster to email: info@camraredisease.org

If required we can supply a PowerPoint Poster template on request

At an EU Conference in 2013 I displayed a poster of the many conditions affecting Alström patients, this was spotted by chance by the CEO of Prometics, resulting, after overcoming barriers, with the first UK clinical trial for their PBI-4050 fibrosis treatment. The drug gained EU and US Orphan drug status this year.

We want to give other Rare Disease patients and groups the opportunity to have maximum exposure to pharma and biotech companies, trusts and clinicians.

Here is your **chance** to have your **patient journey** circulated and **exhibited** at the summit.

www.camraredisease.org

CRDN Cambridge Rare Disease Network
Valuing. Celebrating. Supporting.