

The power of the patient voice in research

[glossary_exclude]As part of GSK's Focus on the Patient programme, I connect GSK researchers with the patients they are ultimately developing medicines for. This provides our researchers with insights into the challenges of living with a disease, enabling us to incorporate patient feedback directly into our R&D process.

When I cast my mind back, one of the first things that struck me was that almost every patient I met was so courageous, strong and determined that their disease would not totally define them. By sharing their experiences with GSK they, like I, wanted to make a difference.

In 2011 I had the opportunity to join the European Patients' Academy project to represent GSK, and I didn't hesitate to sign up. I want to see a greater increase in patient involvement within research so that patients become a key partner in drug development discussions and much earlier in the process.

The power of the patient voice is phenomenal, and inspires, motivates, informs, challenges and advises us during our awareness seminars. At GSK, we work hard to bring a new medicine for the disease being discussed, but don't often get the opportunity to hear directly from a patient, let alone interact with them; other employees have family members living with the disease being discussed and want to learn more, while other employees are patients themselves.

It may sound simple – share your experience and raise awareness; however the patient voice goes far beyond storytelling. Many patients reveal the challenges they have faced getting a proper diagnosis, going through treatment regimes,

what taking medicines is like, how it is to be a clinical trial participant, the hurdles of getting access to medicines, the side effects of treatment, remembering to take their medicine(s), their unmet needs and what they'd like to see from future medicines and research.

One such patient is Nikki, who since taking part in our seminar on scleroderma in October 2012 has been inspired to become an advocate for other patients, and to raise awareness in the UK national press. She is an expert with the European Medicines Agency and EURORDIS, and recently joined a specialised rheumatology health group advising the NHS. [link to blog]

Nikki says "Having had my world turned upside down in 1997 due to my systemic sclerosis diagnosis, the Focus on the Patient program has not only given me hope that a cure will be discovered, ... but also has provided a platform for me to share the day-to-day challenges of living with this condition, and highlight potential areas for future treatments."

And Nicola who, since speaking to GSK at the end of April 2014 about her fight with bowel cancer, has now been able to turn a negative experience into a positive one by reaching out to others via her blog. [link to blog]

As a member of EUPATI, I see the drive for patient involvement in research gaining momentum day-by-day and week-by-week, from many different angles. A really good thing for patients and for society. [/glossary_exclude]