



Advocacy and becoming involved

In this video from the CLLSA UK Patient Meeting in Cambridge, 21st June, 2014, Patient Advocate Andrew Schorr chairs a panel of UK patient advocates in a discussion of the important roles that advocacy can play in living with and raising awareness of less understood diseases such as CLL. From small 'a' to large 'A', the panel traces the impact of advocacy from the personal to the political and the local to the global.

video <http://youtu.be/9882LmKVMRc>

Kath Parson from OPAAL (Older People's Advocacy Alliance), adds her professional perspective to the experiences of CLL patient advocates Julia Kennedy and Tricia Gardom. Andrew, Julia and Tricia share their experiences in the transformation from patient to advocate and discuss what motivated them.

The panel concludes that advocacy works at a number of levels, beginning with the immense day to day benefits that sharing experiences with other patients in support groups brings to those living with CLL. From the positive impacts on the sense of isolation, fear and powerlessness that often accompanies diagnosis, grow more strategic advocacy campaigns such as lobbying for improved access to costly transformational therapies among the CLL community. Finally, the panel considers the potential benefits to the patient and clinical communities of collective individual experience on-line providing a global insight into living with CLL. All agreed that, whilst face to face support was important, staying connected online was an increasingly effective source of networked empowerment.

CLLSA Cambridge conference report

<https://healthunlocked.com/clisupport/posts/130922126/cllsa-in-cambridge-june-20-21st-2014>

Video - Positive News & Developments in Chronic Lymphocytic Leukaemia From The EHA June 12-15

Professors Simon Rule, Peter Hillmen and John Gribben are leading UK clinical researchers with a special interest in CLL. In this brief news report from this year's EHA meeting in Milan they share insights into the promising future for CLL treatment as greater understanding of the biology of this

complex disease brings with it an increasing range of potential therapies.

Video <http://youtu.be/SxYBcO9Y8VQ>

New treatments bring new economic challenges. Many of these novel therapies target very specific cellular activity, reducing the toxic side-effects of the chemoimmunotherapy regimes currently forming the mainstay of CLL treatment in the UK. Unlike chemo, they require long-term daily administration with consequent increased costs and implications for access. The specialist clinicians in the video address the importance of empowering patients to lobby for better access to these transformational therapies in today's challenging financial climate.

<http://www.clisupport.org.uk>

<https://healthunlocked.com/clisupport>