Victory for Essex patient fighting for treatment

Tuesday 22 May, 2018

Daniel Alexander from Harwich in Essex recently contacted the patient charity National Society for Phenylketonuria (NSPKU) about problems he was having accessing treatment for his rare disease (phenylketonuria or PKU).

This rare disease is characterised by the inability to metabolise phenylalanine within protein. The standard treatment is a special low protein diet, which requires prescribed foods and supplements.

Daniel had not been on treatment for many years but began to be concerned about his health. Daniel decided to return to dietary treatment after an MRI scan and consultation with his hospital. However, the NHS funding authority in his area - North Essex CCG - refused to fund any treatment for his PKU. Daniel has been waiting for this decision to be reversed for two years, which he says was very stressful and frustrating.

The NSPKU wrote to Daniel's MP Bernard Jenkin who immediately took the action of writing to the Chief Executive of NHS North Essex CCG about the situation. We are pleased to say that the health authority backed down within days of receiving the letter and have agreed to fund Daniel’s treatment.

Daniel said “I am relieved this has been resolved at last. I am looking forward to taking control of my PKU again. If any other people are struggling with getting the treatment or products they need you should challenge the NHS. The NSPKU and my MP were very supportive.”

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