Cystic Fibrosis a fight we must win

Janet Finch-Saunders AM
Chair, Petitions Committee
National Assembly for Wales
Cardiff Bay
CF99 1NA

6 December 2019

Dear Janet

Thank you for your letter following the closure of the petition for access to cystic fibrosis medicines in Wales.

It was our pleasure to be able to support the cross-party effort to ensure this issue was properly scrutinised by the National Assembly for Wales and we thank you for your enduring support through to a satisfactory outcome. People with cystic fibrosis and their families endured an agonising wait, but the persistent representations of the Committee provided important reassurance that their plight was not forgotten.

In 2020, we expect the European licensing of a fourth cystic fibrosis treatment from Vertex Pharmaceuticals. A triple-combination drug therapy (branded Trikafta™ in the USA). The data for the drug shows stunning impact on lung function, and critically that the drugs can help a far wider group of people with CF than Orkambi, Symkevi and Kalydeco. We estimate that this could increase the number of people in Wales eligible to receive these medicines to 90% of those with the condition.

It is of paramount importance that we do not have a repeat of the protracted negotiations once the medicine has received its license from the European Medicines Agency. We will keep you updated on progress and I am hopeful that the work that has been done has laid the foundations for swifter access to future therapies and we will continue to fight for people with cystic fibrosis to have access to the expanding set of advanced medicines that are being developed, as soon as possible.

Thank you again for your support.

Yours sincerely

David Ramsden
Chief Executive

Cystic Fibrosis Trust 2nd Floor, One Aldgate, London, EC3N 1RE
020 3795 1555 cysticfibrosis.org.uk enquiries@cysticfibrosis.org.uk
Patron: His Royal Highness The Prince of Wales, KG, KT, GCB, OM

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