Consultation feedback: Dornase alfa transition to Special Authority

Pharmac
Via email: cfpanel@pharmac.govt.nz

I am writing on behalf of Cystic Fibrosis NZ to express our support for the proposal to transition the process for obtaining funded access to dornase alfa (Pulmozyme) from the cystic fibrosis (CF) Panel to a standard Special Authority.

We would like to acknowledge and thank PHARMAC for developing this proposal.

About Cystic Fibrosis NZ
Cystic Fibrosis NZ is the only charity dedicated to supporting and improving the quality of life for people with Cystic Fibrosis and their families.

Established in 1968 as a volunteer support group for parents with a newly diagnosed child, we dedicate ourselves to shaping a brighter future for everyone with Cystic Fibrosis. We do this through local family and individual support by our team of social workers, by covering the cost of essential medical equipment, providing organ transplant assistance, information packs, welfare assistance and many other means of support. We also fund Cystic Fibrosis research and advocate on behalf of the community for better access to services and care.

Streamlining access to dornase alfa would have significant benefits for cystic fibrosis patients and their families
Dornase alfa provides significant benefits to cystic fibrosis patients by improving their lung health and their daily lives.

The current requirement for spirometry to commence treatment is time consuming, and places a significant burden on patients and their families. Families of younger patients find fitting in three lung function tests over 6 weeks hard to manage, while many adult patients face difficulties in accessing these tests while holding down full-time, busy jobs or study. Some also risk losing money because they are not paid for time off, having exhausted leave from hospital stays.

Managing the current arrangements is also time consuming for staff, including organising appointments, carrying out the lung function tests, and submitting applications. Cystic Fibrosis NZ supports the proposed new access arrangements for dornase alfa as they will ease the burden on patients, their families and staff.

Cystic Fibrosis NZ understands that the proposed new criteria may potentially widen the range of patients eligible to access dornase alfa. Under current criteria, a number of cystic fibrosis patients have derived significant benefit from trials of dornase alfa, but have unfortunately not met the criteria to qualify for access. These benefits include improved sleep, exercise tolerance, lung clearance, and general well-being.

Cystic Fibrosis NZ strongly supports the introduction of criteria which would simplify and widen access to a medicine which plays such an important role for cystic fibrosis patients.

It is essential, however, that no cystic fibrosis patients are disadvantaged through the proposed change to access criteria. For those currently receiving dornase alfa, we acknowledge Pharmac's commitment that all current full supply approvals will be transitioned over to new approvals to ensure continuation of funded access to treatment. It will also be important to ensure that the proposed new criteria do not result in patients who may have qualified under the current arrangements not being eligible under the new criteria.

Conclusion
We support the proposal to transition funded access to dornase alfa to a standard Special Authority.

Thank you for the opportunity to provide feedback on this proposal. We are available should you wish to discuss anything raised in this submission.

Kind regards

Sue Lovelock
Acting Chief Executive
Cystic Fibrosis New Zealand
16 October 2020