

The National Kidney Federation is pleased that the second set of recommendations address a number of our original worries, however we still feel that our patients are going to suffer unnecessarily unless further changes are made. Patients are at risk from their calcium and phosphate levels, not just their PTH. We know that these 3 things are the key to measuring if a patient has hyperparathyroidism and if they are likely to have problems with calcium in their arteries and muscles. Controlling calcium and phosphate is difficult, but is essential for the long term health of dialysis patients. We believe that if a patient's calcium remains too high, even after taking all the medication and sticking to diets, then surely they should be eligible for this new drug. Your latest recommendation means that patients will now have access to this new drug but only if they have a very high PTH, you seem to take no account of whether their calcium or phosphate is too high. If a patient's medication is not working and their condition is getting worse, having to wait until their PTH goes through the roof could mean that they are being put at great risk. You also say that the new drug should not be made available unless they cannot have a parathyroidectomy operation. The NKF strongly believes that such an operation is not necessary ( or the best treatment ) when they now have the option of a single daily tablet to control their PTH level. It should not be assumed that complicated neck surgery is an acceptable option for patients who have to undergo 3 hours of dialysis 3 times a week for the rest of their life, or until they are fortunate enough to get a transplant. If the parathyroid gland is removed and a patient then has a transplant they will face a life of uncontrollable bone disease, whereas if patients can take the new drug when their other medication no longer works (whatever their PTH or fitness for surgery) you have given their doctor the chance to control a patient's bone disease. We would ask you to think again about the restrictions that you are placing on the use of this drug. We feel that our patient members, who have a very poor quality of life on dialysis should not be subjected to extra surgery when an alternative exists. We are also not convinced that a parathyroidectomy is very effective in very many of the cases.