

	Case 1	Case 2	Case 3
Age at diagnosis	1st month of life	1st month of life	1st month of life
Genetic results	Heterozygous nonsense <i>ABCC8</i> gene mutation (c.2464C>T, p.Gln822Ter)	Heterozygous missense <i>KCNJ11</i> mutation (c.119G>A, p.G40D)	Heterozygous missense <i>ABCC8</i> mutation (p.G1401R)
PET scan results	Pancreatic head focal lesion	Pancreatic head focal lesion	Pancreatic head focal lesion
Surgery	None	Three lesionectomies	None
Diazoxide maximal dose (mg/kg/day)	20	15	20
Octreotide maximal dose (mcg/kg/day)	40	40	35
Sirolimus maximal dose based on concentrations up to 15ng/ml (mg/m ² /day)	6	16	Not tried
Feeding plan prior to Lanreotide	Daytime 2 hourly PEG feeds Overnight PEG feeds	Day-time 3 hourly PEG feeds Overnight PEG feeds	3-4hourly oral feeds daytime and overnight
Age of commencement of Lanreotide	11 months	9 months	20 months
Initiation of Lanreotide dose	30mg/4 weeks	30mg/4 weeks	30mg/4 weeks
Age of last clinic review	23 months	3 years	27 months
Current weight	12.5 kg (+0.21 SDS)	14.15 kg (- 0.18 SDS)	10.75 kg (- 1.52 SDS)
Current height	84cm (-0.66 SDS)	90cm (-1.1 SDS)	84.7cm (+0.02 SDS)
Current height velocity	12cm/year (+1.16 SDS)	9cm/year (+0.48 SDS)	6.5cm/year (-1.9 SDS)
Current biochemistry (TFT, LFT, IGF1/IGFBP3)	Normal	Normal	Normal
Gallbladder USS	Normal	Normal	Small gallstones
Current feeding plan	3 hourly PEG feeds daytime (12% carbohydrate) overnight PEG feeds	4 hourly Neocate advance daytime and overnight PEG feeds	4-6 hourly feeds (food and Similac)
Current Lanreotide dose	30mg/4 weeks	30mg/5 weeks	30mg/4 weeks
Duration of fast while on Lanreotide	Up to 3 hours	Up to 8 hours	Up to 12 hours