

DIETETIC NATIONAL FORMULARY FOR INHERITED METABOLIC DISORDERS ADULTS AND PAEDIATRICS

Acknowledgement:

Anne Daly
Chair of BIMDG-DG

BIMDG DIETETIC METABOLIC FORMULARY

INTRODUCTION

www.bimdg.org.uk.

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DISORDERS REQUIRING LOW PROTEIN DIETS

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EA CYCLE DISORDERS	

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IFDIUM (CHAIN FATTY ACID OXIDAT	ION DISORDERS: F	MFRGFNCY	REGIMENS	CONTROLLED FAST
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EMERGENCY REGIMENS

NUTRITIONAL SUPPLEMENTATION/ SUPPORT

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GLOSSARY OF TERMS

ACBS

BIMDG

AA

СНО

CGMP

DHA

EPA

FOS

GOS

LCPUFA

LCT

MCT

PHE

AMINO ACIDOPATHIES

Protein substitutes

HOMOCYSTINURIA (HCU)
Background information
Dietary treatment requires:
•
•
•

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Administration:
Pregnancy Pregnancy is often a time of intensified dietary management and the use of new dietary products may be essential.
Pregnancy may occur without planning with unsafe metabolic control on patient presentation. Regaining
metabolic control is considered a matter of urgency, with strict dietary management being implemented immediately. Therefore, dietary prescription products may be needed on an urgent basis having not been used before/in adulthood.

Table 1

Name	Unit size	Age	Flavour	Source of protein	Protein g per 100g per 100mL	Protein g per unit size	Energy Kcal per unit size	CHO g per unit size	Fat g per unit size	Vitamins Minerals supplemented to provide complete profile	LCPUFA Novel Ingredients	ACBS listed PIP code		
COMPANY:	COMPANY: NUTRICIA LTD													

COMPANY:	VITAFLO						

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			<u> </u>				

MAPLE SYRUP URINE DISEASE (MSUD)
Background information
Dietary treatment requires:
•
•
Protein substitutes
Dosage of protein substitute:
•
•
•

Dosage of valine and isoleucine supplementation	
Administration:	
Pregnancy	
intensified dietary management and the use of new dietary products may be essential.	Pregnancy is often a time of
EMERGENCY MANAGEMENT.	
Ingredients added to emergency regimens include:	
•	
•	
•	
Dose:	
Administration .	
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<u>See BIMDG emergency guidelines for further information</u>

Table 2

Product name	Unit size	Age	Flavour	Protein source	Protein g per 100g per 100mL	Protein g per unit size	Energy Kcal per unit size	CHO g per unit size	Fat g per unit size	Vitamins Minerals supplemented to provide complete profile	LCPUFA Novel Ingredients	ACBS listed PIP code
COMPANY: NUTRICIA LTD												

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	5g unit										
COMPANY: \						1					
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PHENYLKETONURIA (PKU)
Background information
Dietary treatment requires:
•
•
Role of protein substitute
Dosage of protein substitute
•

• •	
Administration of protein substitutes:	
Pregnancy	
presentation. Regaining metabolic control is considered immediately.	Pregnancy may occur without planning with unsafe metabolic control on patient a matter of urgency, with strict dietary management being implemented
Additional notes	

Table 3

Name	Unit size	Age	Flavour	Protein source	Protein g per 100 g per 100mL	Protein g per unit size	Phe content mg per unit size	Energy kcal per unit size	CHO g per unit size	Fat g per unit size	Vitamins and minerals supplemented to provide complete profile	LCPUFAs Novel ingredients	ACBS listed PIP code
COMPANY: CA	MBROOKE	THERAPEU	TICS										

Name	Unit size	Age	Flavour	Protein source	Protein g per 100g per 100mL	Protein g per unit size	Phe content mg per unit size	Energy kcal per unit size	CHO g per unit size	Fat g per unit size	Vitamins and minerals supplemented to provide complete profile	LCPUFAs novel ingredients	ACBS listed PIP code
COMPANY: G	ALEN												

Name	Unit size	Age	Flavour	Protein source	Protein g/100 g	Protein g per unit size	Phe content mg per unit size	Energy kcal per unit size	CHO g per unit size	Fat g per unit size	Vitamins and minerals supplemented to provide complete profile	LCPUFAs novel ingredients	ACBS listed PIP code
COMPANY: M	IETAX												

Name	Unit size	Age	Flavour	Protein source	Protein g/100 g	Protein g per unit size	Phe content mg per unit size	Energy kcal per unit size	CHO g per unit size	Fat g per unit size	Vitamins and minerals supplemented to provide complete profile	LCPUFAs novel ingredients	ACBS listed PIP code
COMPANY: M	IEVALIA						l .	l .	l .				

Name	Unit size	Age	Flavour	Protein source	Protein g pre100 g per 100mL	Protein g per unit size	Phe content mg per unit size	Energy kcal per unit size	CHO g per unit size	Fat g per unit size	Vitamins and minerals supplemented to provide complete profile	LCPUFAs Novel Ingredients	ACBS listed PIP code
COMPANY:	NUTRICIA							l		ı	1		

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Name	Unit size	Age	Flavour	Protein source	Protein g per 100 g per 100mL	Protein g per unit size	Phe content mg per unit size	Energy kcal per unit size	CHO g per unit size	Fat g per unit size	Vitamins and minerals suppleme nted to provide complete profile	LCPUFAs novel ingredients	ACBS listed PIP code	
COMPANY: VI	COMPANY: VITAFLO UK													

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	Red					
	White					
	Green					
	Gold					

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Yellow			
Red White Green			
Gold			
Yellow			

TYROSINAEMIA
Background information
Dietary treatment for Tyrosinaemia type I and II requires:
, , , , , , , , , , , , , , , , , , , ,
•
•
• • • Dietary treatment for Tyrosinaemia type III
• • •
• • • Dietary treatment for Tyrosinaemia type III
• • • Dietary treatment for Tyrosinaemia type III •

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• • • •	
Protein substitutes Administration:	
Administration:	
Pregnancy	Pregnancy is often a time of intensified dietary management
and the use of new dietary products may be essential. Alkaptonuria (AKU)	Pregnancy is often a time of intensified dietary management
Aikuptoliuliu (Aiko)	off label

Table 4

			of protein	Protein g per 100g per 100ml	Protein g per unit size	Energy Kcal per unit size	CHO g per unit size	Fat g per unit size	minerals supplemented to provide complete profile	LCPUFAs Novel Ingredients	ACBS listed PIP code		
COMPANY: NUTRICIA LTD													
	NUTRICIA LT									NUTRICIA LTD	NUTRICIA LTD		

COMPANY: 0	GALEN					I		
						1	1	

GLUTARIC ACIDURIA TYPE 1 Background information Dietary treatment requires: Protein substitutes

Dosage of protein substitute

ORGANIC ACIDURIAS

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Protein substitute
Administration:
Pregnancy
Pregnancy is often a time of intensified dietary management and the use of new dietary products may be essential (particularly protein
substitutes).
EMERGENCY MANAGEMENT
emergency regimen
 lysine-free, low tryptophan amino acid supplements

<u>See BIMDG emergency guidelines for further information.</u>

Table 5

Name	Unit size	Age	Flavour	Protein source	Protein g per 100g per 100mL	Protein g per unit size	Energy Kcal per unit size	CHO g per unit size	Fat g per unit size	Vitamins and minerals suppleme nted to provide complete profile	LCPUFAs Novel Ingredients	ACBS listed PIP code
COMPANY: N	UTRICIA LTI	<u> </u>			•							
COMPANY: VI	TAFLO LIK											
COM ANT. VI	IAI LO OK											

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METHYLMALONIC ACIDAEMIA AND PROPIONIC ACI	DAEMIA (MMA/PA)
Background information	
Dietary treatment	
Protein substitutes Infancy	
Children/Adults/Pregnancy ene	ergy supplements
Dosage of protein substitute/precursor free amino	acids

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Administration

EMERGENCY REGIMENS

<u>See BIMDG emergency guidelines for further information.</u>

Table 6

Name	Unit	Age	Flavour	Protein source	Protein g per 100g per 10mL	Protein g per unit size	Energy Kcal per unit size	CHO g per unit size	Fat g per unit size	Vitamins Minerals suppleme nted to provide complete profile	LCPUFA Novel Ingredients	ACBS listed PIP code
COMPANY: N	UTRICIA LT	D I	1				1					
COMPANY: V	ITAELO LIK											
COIVIPAINT: V	TAPLO UK											

Energy supple	ments						
••							

ISOVALERIC ACIDAEMIA (IVA)
Background information
Dietary treatment
Protein substitutes Infancy:
mancy.
Children/Adults/Pregnancy

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energy supplements table 16

Dosage of protein substitute

Administration

EMERGENCY REGIMEN

<u>See BIMDG emergency guidelines for further information.</u>

Table 7

Name COMPANY: N	Unit size UTRICIA LTI	Age	Flavour	Protein source	Protein g per 100g per 100mL	Protein g per unit size	Energy Kcal per unit size	CHO g per unit size	Fat g per unit size	Vitamins Minerals supplemented to provide complete profile	LCPUFA Novel Ingredients	ACBS listed PIP code	
	COMPANY: NUTRICIA LTD												
COMPANY: V	ITAFLO UK	1	1		T	1	T	1	1	T		T	
Energy supple	ements												

PYRIDOXINE DEPENDENT EPILEPSY (PDE)/ ANTIQUITIN DEFICIENCY **Background information** see GA1 dietary treatment). **Dietary treatment requires: Protein substitutes** Dosage of protein substitute

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UREA CYCLE DISORDERS	
Background information	
Dietary treatment requires:	
•	
•	
• •	
•	
Essential amino acids	
Children/Adults/Pregnancy	
Essential amino acids:	
Essential amino acids are given at least	
Administration:	
	Daga 40 of 00

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Energy supplements

Pregnancy

Pregnancy is often a time of intensified dietary management and the use of new dietary products may be essential. Pregnancy may occur with no dietary treatment in place. However, regaining metabolic control is considered a matter of urgency, thus prescription products may be needed on an urgent basis having not been used before/in adulthood

EMERGENCY REGIMEN

See BIMDG emergency guidelines for further information.

Table 8

Name	Unit size	Age	Flavour	Source of protein	Protein g per 100g per 100mL	Protein g per unit size	Energy Kcal per unit size	CHO g per unit size	Fat g per unit size	Vitamins and minerals supplemented to provide complete profile	LCPUFAs Novel Ingredients	ACBS listed PIP code
COMPANY: NU	JTRICIA LTD											
	Dose 5g											
COMPANY: VI	TAFLO UK	1	T	Ī	1	1	T	1	T			
Energy supple	ments		1		I	I	1	l	1	1		

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OTHER CONDITIONS NEEDING PROTEIN RESTRICTION

3	HADBUXA 3	MFTHYLGLUTARYL	HMG-COA	I VASE DEFICIENCY	,
3	пиркила	IVII I HILLIGLU I AN I L	HIVICI-CUA	LIASI DIFICIINCI	

Background information

Dietary treatment requires:

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Administration

EMERGENCY MANAGEMENT

<u>See BIMDG emergency guidelines for further information.</u>

GYRATE ATROPHY / 0	ORNITHINE AMINOTRANSFERASE	E DEFICIENCY	
Background informat	tion		
Dietary treatment re	quires:		
•			
•			
•			
•			
•			
Essential amino acids	_		
Essential amino acids	;		
Dose of essential am	ino acids:		
Administration			
Duradicate considing the		formalin tables 4C 47 and 0	
Products used in the	treatment of gyrate atrophy are	tound in tables 16,17 and 8	
Energy supplements			
Vitamin and mineral/ essentia	l fatty acid supplements	Page 52 of 99	
Essential amino acid suppleme	ent	Return to CONTENTS	

SINGLE DOSE L- AMINO ACIDS Background information

•

•

•

Administration:

Emergency management:

Table 9

Name	Unit size	Age	Flavour	Source of protein	Protein g / 100g	Protein g per unit size	Energy Kcal per unit size	CHO g per unit size	Fat g per unit size	Vitamins Minerals supplemented to provide complete profile	LCPUFA Novel Ingredients	ACBS listed PIP code
COMPANY: NUT	RICIA LTD	Ι	T	T	1	T	T	1	Π		T	T

COMPANY: VITA	AFLO UK						

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DISORDERS OF FAT METABOLISM

FATTY ACID OXIDATION DISORDERS

DISORDERS OF LONG CHAIN FATTY ACID OXIDATION

Defects of the carnitine cycle

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- •

Defects of β-oxidation

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- •
- •

Background information

Treatment requires:

- •
- •
- •
- •

MCT products for long chain fatty acid oxidation disorders
Dose:
Administration:
Pregnancy Pregnancy is often a time of intensified dietary management and the use of new dietary products may be essential. Pregnancy may occur with no dietary regimen in place, however, regaining metabolic control is considered a matter of urgency, thus prescription products may be needed on an urgent basis having not been used before/in adulthood.
EMERGENCY MANAGEMENT
See BIMDG emergency guidelines for further information.

Table 10

Unit size	Age	Flavour	Fat source	Protein g per unit size	Energy Kcal per unit size	CHO g per unit size	Fat g per unit size	Vitamins and minerals supplemented to provide complete profile	LCPUFA Novel Ingredients	ACBS listed PIP code
UTRICIA LTD								_		_
ITAFLO UK			1				1	1		
	UTRICIA LTD	UTRICIA LTD	UTRICIA LTD	UTRICIA LTD	UTRICIA LTD	UTRICIA LTD	UTRICIA LTD	UTRICIA LTD	per unit size unit size unit size per unit size supplemented to provide complete profile UTRICIA LTD	UTRICIA LTD per unit size unit size unit size per unit size per unit size per unit size unit size unit size unit size per unit size unit si

Medium chain acyl CoA dehydrogenase (MCADD) deficiency						
Background information						
MCT products are contraindicated.						

KETOGENIC DIETS (KD) AND GLUCOSE TRANSPORTER 1 (GLUT1) DEFICIENCY

KETOGENIC DIETS

Background information

Type of ketogenic diets

- •
- •
- •

GLUT 1 DEFICIENCY

Background information

Table 11

Name COMPANY: N	Unit size	Age	Flavour	Fat source	Protein g per unit size	Energy Kcal per unit size	CHO g per unit size	Fat g per unit size	Vitamins and minerals supplemented to provide complete profile	LCPUFA Novel Ingredients	ACBS listed PIP code
COMPANT. N	OTRICIA LID										

COMPANY: VI	TAFLO LTD					

X LINKED ADRENOLEUKODYSTROPHY (X-ALD)/ ADRENOMYELONEUROPATHY (AMN)
Background information
Dietary treatment requires:
•
•
•
•
Dose of Lorenzo/GTO oil
Administration

Table 12

Name	Unit size	Age	Flavour	Source of fat	Fat per 100g	Fat g per unit size	Energy Kcal per unit size	CHO g per unit size	Protein g per unit size	Vitamins and minerals supplemented to provide complete profile	LCPUFA Novel Ingredients	ACBS listed PIP code
COMPANY: N	NUTRICIA L	ΓD										

DISORDERS REQUIRING A MODIFIED CARBOHYDRATE DIET

GLYCOGEN STORAGE DISEASES (GSD)			
Background information			
Dietary treatment requires:			
•	Glycosade		
•	/ Glycosade		
	, - ,		
Dose: Glucose polymer)	
Slow release carbohydrate (cornstarch/ <i>Gi</i>	lycosade)

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Administration	
Protein supplementation	
Pregnancy	
products may be essential.	Pregnancy is often a time of intensified dietary management and the use of new dietary
EMERGENCY MANAGEMENT	
See BIMDG emergency guidelines for further inforn	nation.

Table 13

COMPANY: N	JTRICIA LTI	D									
COMPANY: VI	TAFLO UK										
Slow release of	arbohydra	te supple	ments								
Name	Unit size	Age	Flavour	Carbohydrate source	Energy kcal per unit size	CHO g per unit size	Protein g per unit size	Fat g per unit size	Vitamins and minerals supplemented to provide complete profile	LCPUFA Novel Ingredients	ACBS listed PIP code
COMPANY: VI	TAFLO LTD										
COMPANY: SU	JPERMARK	ETS			•	•	•	•			

GALACTOSAEMIA	
Background information	
Dietary treatment requires: •	
•	
Dose of lactose free infant formula:	
Administration:	
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Table 14

Name	Unit size	Age	Source of protein	Protein g 100mL / unit size	Energy Kcal unit size	CHO g / unit size	Fat g / unit size	Vitamins and minerals supplemented to provide	LCPUFA Novel Ingredients	ACBS listed PIP code	
COMPANY: SMA nutrition											
COMPANY: M	EAD JOHNS	SON									
COMPANY: NUTRICIA LTD											

CITRIN DEFICIENCY OR CITRULLINEMIA TYPE II (CTLN2)
Background information
Dietary treatment requires:
•
•
•
•
Protein and fat supplements
Dose:
ENACTOCING DECINATION
EMERGENCY REGIMEN
See BIMDG emergency guidelines for further information.

Table 15

COMPANY: NUTRICIA LTD											
			_								
COMPANY: VITAFLO LTD											
COMPANY: HOLLAND AND BARRETT	Unit size	Age	Flavour	Source of protein	Protein g per 100g	Protein g per unit size	Energy Kcal per unit size	CHO g per unit size	Vitamins and mineral supplemented providing complete profile	LCPUFA Novel Ingredients	ACBS listed PIP code
COMPANY: HOLLAND AND BARRET											

EMERGENCY REGIMENS reference to energy supplements table 16
Background information
Administration
Dosage
See BIMDG emergency guidelines for further information.

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KETOTIC HYPOGLYCAEMIA (KH)
Background
EMERGENCY REGIMEN table 16
See BIMDG emergency guidelines for further information.

ENERGY SUPPLEMENTS
Background information
*
•
•
•
•
•
*Fat emulsions may be contraindicated in some metabolic conditions
Dose of energy supplements
Administration:
PROTEIN SUPPLEMENTS

Table 16

Name	Unit size	Age	Flavour	Carbohydrate, fat or protein source	Energy kcal per unit size	CHO g per unit size	Protein g per unit size	Fat g per unit size	Vitamins Minerals suppleme nted to provide complete profile	LCPUFA Novel Ingredients	ACBS listed PIP code
COMPANY: N	UTRICIA										
Carbohydrate	energy sur	plements					1				
Fat energy sup	pplements	<u> </u>									

Carbohydrate	and fat end	ergy supplem	nents						
Protein energy	y suppleme	nts							
	1		1	l	1	1		1	

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COMPANY: V	TAFLO UK										
Name	Unit size	Age	Flavour	Carbohydrate, fat or protein source	Energy Kcal per unit size	CHO g per unit size	Protein g per unit size	Fat g per unit size	Vitamins Minerals suppleme nted to provide complete profile	LCPUFA Novel Ingredients	ACBS listed PIP code
Carbohydrate	energy sur	plements									
											353 10
											15 20 25
											25
Fat energy su	pplements										
Carbohydrate	and fat en	ergy supplem	nents		<u> </u>		I	<u> </u>			

Protein energ	gy suppleme	ents									
COMPANY: I Protein sup											
ProSource	45mL	3y-adult	Neutral	Protein	44	1	11	0	No	None	348-9622
ΓF	sachet		110000101	hydrolysed				Ů	110	110110	
	powder			collagen							

VITAMIN AND MINERAL / ESSENTIAL FATTY ACID SUPPLEMENTS
Background information
Dose
Administration
Essential fatty acids (EFA)

Table 17

Name	Unit size	Age	Flavour	Source of protein	Protein g 100g	Protein g per unit size	Energy Kcal per unit size	CHO g per unit size	Fat g per unit size	Vitamins Minerals supplemented to provide complete profile	LCPUFA Novel Ingredients	ACBS listed PIP code
COMPANY:	NUTRICIA LTD											
COMPANY:	 VITAFLO UK											
						04 - 600						

COMPANY: A	ALLIANCE PHARM	MACEUTICA	ALS	T							
_											
			••••								
COMPANY: I	SSENTIAL PHAR	MECEUTIC	ALS LID	<u> </u>	ī	T		1	T	T	

FLAVOUR SACHETS

Table 18

rable 19												
Name	Unit size	Age	Flavour	Protein source	Protein g per 100g per 100mL	Protein g per unit size	Energy Kcal per unit size	CHO g per unit size	Fat g per unit size	Vitamins and minerals supplemented to provide complete profile	LCPUFA Novel Ingredients	ACBS listed PIP code
COMPANY:	NUTRICIA LT	D					•	•				
COMPANY	VITAFLO U	IK				T	T	1	T			
												-

SPECIAL LOW PROTEIN FOODS FOR USE WITH LOW PROTEIN DIETS

Background information

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Table 19 monthly

PLEASE NOTE:

Table 20

ACBS low protein prescribed foods	Definition of one unit	Suggested size of unit
Pasta/Rice	1 box	Up to 500g
Pasta pots / potato pots/pasta in sauce/XPots	1 pack/box	Up to 300g
Flour mix/cake mix/waffle mix	1 pack/box	Up to 500g
Bread/bread rolls	1 pack	Up to 600g
Pizza bases/pizza base mixes	1 pack	Up to 300g
Crackers/crispbread /mini crackers /croutons/ bread sticks/savoury snacks	1 pack/box	Up to 200g
Sausage/burger mixes/fish substitutes	1 pack/box	Up to 360g dry powder
Cheese sauce mix	1 pack	Up to 225g dry powder
Soups	1 box	Up to 112g dry powder
Breakfast cereals	1 box/pack	Up to 400g
Egg replacer/egg white replacer	1 tub/box	Up to 500g
Yoghurt substitute	1 tub	Up to 400g
Biscuits/biscuit bars	1 pack/box	Up to 200g
Cakes/breakfast bars/dessert powder mixes /jelly powder/ chocolate spread substitute	1 pack/box/tub	Up to 300g
Readymade desserts	1 pack	Up to 500g
Energy bars (Vitabite or Chocotino)	1 pack/box	Up to 175g

PLEASE NOTE

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LOW PROTEIN MILKS

Table 21

Product/Company	Unit Size	Λσο	Pho mg	Lou ma	Energy	CHO a per	Eat a per	ACBS listed
Product/Company	Unit Size	Age	Phe mg per 100mL	Leu mg per 100mL	Energy Kcal per 100mL per 100g	CHO g per 100mL/g	Fat g per 100mL/g	PIP code
COMPANY: TARANIS								
COMPANY: MEVALIA								
COMPANY: NUTRICIA	A LTD							
COMPANY: VITAFLO	LTD					1		

LOW PROTEIN PRODUCTS

Table 22

Product	Unit size	Age	Flavour	Energy	CHO g	Fat g	ACBS listed				
Troduct	Offic Size	760	i iuvoui	Kcal per	per 100g	per 100g	PIP code				
				100g	per unit	per unit					
				per unit							
COMPANY: FATE SPECIAL FOODS	COMPANY: FATE SPECIAL FOODS										
COMPANY: JUVELA		<u> </u>	<u> </u>	<u> </u>		<u> </u>					
COMPANY: METAX			T	T	T						
COMPANY: MEVALIA LTD											

COMPANY: NUTRICIA LTD										

COMPANY: PK FOODS										
COMPANY: PROMIN										

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COMPANY: TARANIS				

t				

COMPANY: VITAFLO LTD									

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