



LEAP STORIES

The Newsletter for Families of Participants in the LEAP Study

A 'Thank you' from Prof. Lack

On May 6, 2009, we reached a major milestone in the LEAP Study -- at 12 noon we enrolled our 640th and final child!

What makes this event so amazing is that it has only been two and a half years since we enrolled our first child in the study in December 2006. To recruit and enroll 640 children in such a short time is truly a remarkable achievement. It speaks volumes of our LEAP parents' dedication to their children's health and the health of children everywhere, as well as the hard work of the LEAP Study team.

I cannot emphasize enough how proud I am of this team. Together, the nurses, dietitians, administrators and doctors that make up our team have exceeded all expectations placed upon them.

A world away, there is another group that deserves our gratitude. In addition to our staff here in London,

our friends at the US National Institute of Allergy and Infectious Diseases and the Immune Tolerance Network have helped us at every step of the way. The support of the Food Allergy Initiative and the UK Food Standards Agency also cannot go without mention.

But the most heartfelt thanks is reserved for you, the parents of our LEAP children. This gift you have given us -- the gift of your family's participation -- is one that we hold very dear. Without you there would be no LEAP Study, and without you we would be no closer to solving some of the mysteries of peanut allergy.

We look forward to getting to know each of you better over the next several years as the study progresses and as we move closer to our goals.



In this issue

Welcome to another issue of the LEAP Newsletter. The past year has been a busy one for us at the LEAP Study, with a great deal of changes and thriving activity taking place. Read on to find out what's been happening behind the scenes!

In this bumper edition, we take a look at the role of the Paediatric Allergy Research Nurse and what exactly is involved in the 30-month Visit. Our Dietetic team provides successful tips on managing faddy eating, and there's another delicious new recipe to try out!

On behalf of the LEAP team, we'd like to thank you all for your continued commitment to the Study, and for your patience and co-operation during our difficult winter period when heavy snow forced us to cancel bookings.

Keep your comments and suggestions coming in. Send your emails to: info@leapstudy.co.uk quoting 'newsletter' in the subject title.

We'd like to hear from you!

Something you'd like to ask one of our doctors, nurses or dietitians? Got a favorite recipe? Website or book recommendation you'd like to share with other LEAP families? Send it to info@leapstudy.co.uk, we'd LOVE to hear from you!

How to manage fussy eaters

by **Tammy Amarra**, BSc (Hons), RD,
Clinical Research Dietitian



It's very common for toddlers to go through phases of being fussy about what they eat - sometimes eating very little, refusing to eat certain foods (even ones they previously liked) or wanting to eat the same thing day after day.

As stressful as this can be, it's rarely harmful. In fact, fussy eating is a normal part of children growing up and asserting their independence.

There are a number of things you can do to manage the situation. Remember, fussy eating is a phase and toddlers do grow out of it.

See our lists of handy "Do's" and "Don'ts" for tips on dealing with a fussy eater.

If you are concerned about your toddler's diet, request a referral to a paediatric dietitian from your GP.

For parents of fussy eating toddlers in the consumption group, please let

DO

- ◆ Encourage family mealtimes – toddlers learn by copying their parents & other children.
- ◆ Offer 3 meals & 2-3 snacks a day around sleeping pattern – toddlers do not eat well if over tired.
- ◆ Allow 20-30 minutes for a mealtime and remove any uneaten food without comment. The more attention you give a toddler for not eating, the more likely they are to refuse food.
- ◆ Offer finger foods and give your toddler their own spoon – toddlers enjoy feeding themselves - accept that mealtimes will be messy.

us know, as we have some recipes and ideas to help increase peanut protein consumption.

Occasionally, there are medical reasons why toddlers may not eat. The most common reasons are constipation, reflux and anaemia. If you suspect your toddler is suffering from any of the above, it is important to seek advice from your GP or health visitor.

More information on fussy eating can be found on the Infant and Toddler Feeding Forum. You can download factsheets for free: Log onto www.infantandtoddlerfeedingforum.org.

DON'T

- ◆ Force feed- this will make the situation worse, your toddler will become upset, stressed & start to dread mealtimes.
- ◆ Insist that your child finishes everything on their plate. Accept when they have had enough. It is important that children learn to recognise when they are full and should be allowed to eat to appetite.
- ◆ Take away a refused meal & offer a completely different one in its place - accept that there are some foods your toddler will not eat. It is important that they get used to family meals. Offer new foods with ones you know they will eat.
- ◆ Do not offer much fluid or a drink of milk if a toddler does not eat their meal. Too much milk and/or juice can reduce a child's appetite. Six to eight drinks a day is adequate (more may be required if a child is active or the weather is hot). Three drinks of milk (120mls/4ozs) are sufficient.

HOW MUCH PEANUT?

Often, parents in the peanut consumption group inform us of their struggle to get the required amount of peanuts into their child's diet. As it turns out, the majority of the time the amount they're eating is more than sufficient! Six (6) grams of peanut protein is the weekly required amount, so to help you get an idea of how to meet the target, we have produced a table below:

FOOD	SERVING	PEANUT PROTEIN
'Sunpat' Peanut Butter	1 teaspoon	2g
	Spreading on 1 slice of bread	3.75g
'Bamba' peanut snack	1 packet (25g)	3g
	2/3 packet (21 sticks)	2g
'Snickers' spread	Spreading on 1 slice of bread	0.8g
Whole peanuts	handful (10g)	2.6g
'Snickers' flapjack	34g bar	1.1g
'Tracker' roasted nut bar	26g bar	1.1g
'Eat Natural' fruit & nut bar	50g bar	1.4g
Crunchy Nut Cornflakes	1 bowl (30g)	0.4g
Crunchy Nut Red	1 bowl (30g)	0.4g
Crunchy Nut Nutty	1 bowl (40g)	0.6g
Crunchy Nut Clusters	1 bowl (40g)	0.5g
Weetabix minis (honey & nut crisp)	1 bowl (36g)	0.7g
'Snickers'	64.5g bar	2.9g
Peanut M&Ms	45g packet	2.6g
Cadbury's Fuse	49g bar	3.4g
Reese's Peanut Butter Cups	1 'cup' (from pack of 3)	1.3 g
Reese's Nutrageous bar	60g bar	7.7g
Mr Tom's Peanut Brittle	40g bar	6.5g
Peanut Snaps	33g bar	5.8g
Satay sauce	typical serving	6.5g
Peanut soup	1 bowl	4.6g

 Leap

Your 30-month Clinical Visit

What To Expect & How To Prepare Your Child

by **Saadia Hussain, RSCN**
Paediatric Allergy Research Nurse

August 2008 was an exciting milestone for the LEAP Study when it opened its doors to the first ever participant undergoing her 30-month clinical visit. Since then, 141 Visit 30 (V.30) appointments have been attended. With a large proportion of patients still yet to reach 2 ½ years of age, this article aims to provide an insight into what to expect from a V.30, why it is so important and the necessary preparations that need to be made.

Those that were present at their child's V.30 will know how similar the clinical procedures are to the previous screening and 12-month visits, such as skin prick testing, measurement of vital observations and a blood test. However, the addition to a V.30 is the assessment of asthma and rhinitis (hayfever), and the testing of aero-allergens such as housedust mite and pets. To fully appreciate why these diagnostic tools and the V.30 itself is so important, one has to first understand the principles underpinning it.

The term 'Allergic March' refers to the lifetime pattern of allergic conditions that occur within a child, and how it progresses from one to another. Eczema usually presents itself within the first few months of life, accompanied soon after by food allergy. Once the eczema starts to settle down, asthma manifests around the age of two, followed later by the onset of rhinitis. This is not to say that all children with

eczema or food allergies will go on to develop asthma or hayfever, but it has shown to be a very typical trend.

This is why the LEAP Study's clinical appointments have been spread out at varying intervals over the five years – in order to monitor the progress of each child's allergies and assessing the potential development of others. What makes the V.30 even more pivotal is the fact that if it is not attended, the child will not have another scheduled visit until the age of five, thus missing out on an assessment of key risk factors that could prove to be detrimental to their health and well-being. By undergoing such assessments, the right treatment can be put in place to enable the child to have a good quality of life.

What happens at V.30?

- Skin Prick Testing of: peanut, sesame, soya, milk & egg
- Measurement of vital observations: Height, weight, skinfold thickness, abdominal girth, heartrate, breathing rate, oxygen saturation rate and temperature.
- Assessment of skin condition / eczema
- Assessment of rhinitis and asthma
- Blood Test – Obtaining IgE's for: peanut, sesame, milk, egg, tree nuts (hazlenut, walnut, cashews, brazil and almond), and aero-allergens (cat, dog, mould, pollen and housedust mite).



- Swabs – cotton scraping of nasal and skin site to check for growth of bacteria / bugs

Following on from our first ever participant's V.30, her mother wrote an account of the experience for others to benefit from. Below is an extract:

“When we walked into the unit, Samantha immediately became shy and frightened, so I sat her on my lap and we read a book together. We met a patient and understanding research nurse who discussed everything we needed to accomplish in the visit, and I told her I would like to be involved as much as possible. With the numbing cream all set, the nurse and I got together with the skin prick test – I wrote the initials of the allergens on Samantha's arm, and the nurse explained to her she would put small drops of water on it. Several pricks later, Samantha became very upset and started

squirming. The nurse was very quick and when she finished, I gave Samantha some chocolate treats I brought with me, and the nurse was at the ready with reward stickers.

After she was weighed and measured, we went to see the phlebotomist who impressed me with the ease of finding the vein and getting it over with as soon as possible. Samantha who was engrossed in playing with the toys on the unit, was told by Dr. Du Toit she was finished and could go home, to which she replied, “but I don't want to go home!”

All in all, it was a good visit. I was very proud of Samantha and despite the tears, we were able to accomplish everything we needed and it seemed in the end that she even had a good time. Subjecting your child to a Study where you're completely volunteering isn't easy, especially when you know it's not the most pleasant experience for your child. I was pleased that with a little forethought, parent participation and a few harmless bribes like chocolate, the experience for Samantha was more of an adventure than anything else.”

Here's what other parents have said of their experiences:

“We weren't made to feel rushed or pressured.”

“The blood test was the most anxious aspect of the visit, but thankfully the numbing cream worked and the blood test went smoothly.”

“Good choice of distraction therapy with toys and DVDs.”

“I was surprised by how compliant my child was with the vital measurements.”

“My son thought the whole thing

was fun, what with the excitement of the train journey into London!”

The Nurses will contact you to

book an appointment for your child's V.30 approximately three months in advance.

PREPARING YOUR CHILD FOR V.30

At 2 ½ years old, children are more aware of their surroundings and naturally become daunted by new encounters. Here are some tips to make the experience less intimidating:

- ♦ Inform your child they are about to embark upon a special trip to London, and exaggerate the events, such as 'the ride on a very fast train' to present it as one big adventure!
- ♦ Explain that there will be some special tests, but that it won't hurt because 'magic cream' will be applied to the skin (local anaesthetic cream used to numb the area prior to the blood test)
- ♦ Explain that the nurse will play with them a game of 'magic drops' – special drops of water that will tickle their arm (the skin prick test)
- ♦ Reassure your child that you will stay with them for the duration of the visit and that it will be very quick (approximately 1 hour for the visit, but longer if distraction therapy is needed for co-operation!)
- ♦ Give encouragement that there will be lots of toys on the unit and videos to watch
- ♦ Give the promise of a small reward afterwards to encourage co-operation, such as stickers or a trip to the park
- ♦ Bring some snacks with you to aid your child's comfort
- ♦ Ensure your child is well on the day and not presenting with a fever or wheeze
- ♦ Ensure short-acting antihistamines such as Piriton have been stopped two days prior to the visit, and long-acting antihistamines such as Cetirizine have been stopped seven days beforehand, as these can interfere with the results of the skin prick test.

A day in the life of...

LEAP Study Nurse LYN CLOUGH

Morning

Arriving at work just before 9a.m, I prepare myself for the busy day ahead with my regular early morning coffee fix. I analyse the diary and plan the day, ensuring the correct allocation of nurses and dietitians to patients.

As my colleagues enter the unit and we exchange our usual flurry of banter, I spend the first half hour of my morning ensuring the equipment is clean and in working order. This includes inspecting the resuscitation trolley, testing the oxygen supply on each bedside is functioning, ascertaining the unit is fully equipped as necessary and that the emergency medications are all within their expiry date.

Once all the safety checks are complete, I grab an armful of patient notes from the daily trolley load of 100 plus – all awaiting phone calls. An immense amount of work it seems, but it is such an important aspect of the Study in that telephone communication is the only method of ensuring our participants are safe and complying with their randomised group. I spend the next 1½ hours engrossed in phone calls; the majority of them are brief as the parents have nothing new to report, but some require additional input, such as blood test results, eczema management tips and medication advice.

The familiar ringing tone of the unit doorbell alerts me that my patient has now arrived. This is an initial 'screening' visit. After explaining the nature of the five year programme and addressing any parental concerns, Dr. Du Toit



Nurse Lyn with a visit 30 participant

obtains participation consent whilst I prepare the relevant paperwork and equipment.

First comes the skin prick test. Many of our LEAP children suffer from severe eczema on their faces. Where this is the case, I carry out the skin prick test on the baby's back as this may be the only patch on his or her body free from eczema. Whilst waiting for 10 minutes to read the test, the baby is undressed so I can check his or her vital measurements such as height, weight, skin fold thickness, abdominal girth, etc.

Delving into a child's history of eczema and related questions enables me to assess the severity of the condition, as well as gaining an insight into how well it is being managed and whether the right treatment is in place. I then check the results of the skin prick test and inform the parents of the results. If a child has tested positive for

various allergens, I talk the parents through the potential reactions that can occur and its treatment, before requesting the dietitian's input on how to manage a very restricted diet. The blood test concludes the visit, and I take the opportunity to grab a quick sandwich before my afternoon patient arrives.

Afternoon

Returning to the unit, I discover the 'baseline' patient has been randomised into the peanut consumption group. As the dietitian prepares the peanut snack ready for the challenge, I undertake the usual safety precautions by checking the child's vital observations and condition of skin, making a note of any redness / eczema patches so I know they were already present before consuming the peanut.

As the dietitian takes over, I

continued on next page...

A day in the life... cont'd from pg 6

proceed with my next patient who is attending the 12-month clinical visit. The visit is straightforward and quick – we manage to get through a skin prick test, blood test, vital measurements and eczema assessment in 45 minutes. No significant changes have taken place since their previous visit, so the advice given was to continue as normal until their next visit at 2 ½ years.

I return back to the baseline patient who has done exceptionally well; she has tolerated the peanut snack, all observations are satisfactory, no reactions have occurred and can therefore, now go home.

With a cup of tea in one hand and the phone in the other, I continue with the remaining phone calls; there's still so many left to ring that even with my colleagues' help, we still won't get round to them all. They'll just have to be added to tomorrow's batch.

As the afternoon draws to an end and I prepare in advance tomorrow's workload, I receive a call from a concerned mother whose child has developed hives after accidentally touching a milk product he is allergic to. I advise her to administer a dose of anti-histamine and remain with her on the phone until she feels reassured. Hives are a common occurrence and a typical response of a contact allergen, but for parents who have never witnessed it, it can be very alarming.

My colleague and I gather the notes from the filing cabinet of all the patients that are due to be phoned tomorrow - fortunately there's not as many as there were today. No doubt there'll be lots to keep us busy on yet another day at the LEAP Study!

A FEW REMINDERS:

- Eczema sufferers should be getting through a 500g tub of emollient on a weekly basis
- Peanut avoidance participants only need to avoid peanuts – other nuts are acceptable unless advised otherwise
- Remember to bring along your receipts on clinical visits if requesting travel cost reimbursement
- Remember to regularly check the expiry date of anti-histamines and Epipens. Go to www.anaphylaxis.org to register for the Epipen expiry alert system
- Remember not to give your child whole nuts due to risk of choking – try crushing them and sprinkling over food instead
- LEAP Study staff will phone you:
 - Weekly – if your child is under 1 year
 - Fortnightly – if your child is over 1 year
 - Monthly – if your child is over 2 ½ years
- The 5 clinical visits on LEAP Study:
 - At screening for enrolment (Visit 1)
 - Baseline - randomisation into consumption or avoidance group (Visit 2)
 - at 1 year old (Visit 3)
 - at 2 ½ years (30 months) old (Visit 4)
 - at 5 years old (Visit 5)

LEAP Facts & Figures

Children screened: **925**

Children who failed screening: **260**
(77 peanut allergic)

Children enrolled: **640**
(98 skin prick test positive)

9 month home visits: **65**

21 month home visits: **304**

Number completed visit 12: **523**

Number completed visit 30: **141**

LEAP STAFF NEWS

So many changes have been taking place within the LEAP Team over the past year, that we just don't know where to begin!

Congratulations to **AINE SHERIDAN** (senior research nurse & manager) who gave birth to a beautiful baby girl in December 2008. Aine returns to the LEAP team later in the year.

With sadness, we had to bid farewell to Research Dietitians **SARAH LACEY & TAMMY AMARRA**. Sarah has relocated in preparation for her forthcoming wedding,

and Tammy is adventurously out travelling the world!

FIONA HENLEY (research nurse) felt she benefitted immensely from working on the LEAP Study, but she has now left the team to pursue a broader experience within the allergy field.

Last but not least, **LORI NIRENSTEIN** (LEAP Co-ordinator) sadly left us in January to embark upon a new life in Jamaica.

On a brighter note, the LEAP Team extends a warm welcome to the

following newcomers:

MONICA BASTING, who has replaced Lori as the LEAP Co-ordinator.

GEMMA ADCOCK, (Data Co-ordinator) who joined the team in November.

MARY FEENEY (Research Dietitian), who joined us in January.

LOUISE COVERDALE (Senior Research Nurse), who recently joined the team.

Gemma's Fabulous Flapjacks

Gemma, the LEAP Study's Data Co-ordinator, has volunteered to share her culinary skills with the world! In fact, this is an old family recipe of hers that has been passed down over the years from generation to generation. They're easy to make and egg-free, and the best thing about it is you can be as adventurous as you like by adding various fruits, nuts or even chocolate!

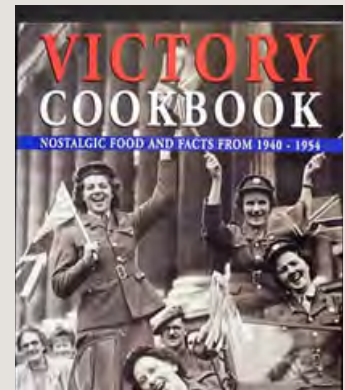
Ingredients:

- 220g soft brown sugar
- 220g butter
- 350g porridge oats
- 2 tablespoons golden syrup
- 1 teaspoon almond essence (omit if almond allergy suspected)

Method:

- 1) Preheat the oven to 150 degrees / gas mark 2.
- 2) Heat the butter, golden syrup and sugar in a saucepan until it melts, stirring gently
- 3) Take off the heat and stir in the porridge oats, almond essence and optional fruit or nuts.
- 4) Pour the mixture into a greased baking tray, pressing down firmly to make it compact
- 5) Bake for approximately 20 minutes, until the mixture is golden brown
- 6) When ready, leave to cool and then cut into equal squares

Top Tip: Do not leave the flapjacks to cool for too long as they will harden, making them difficult to cut



Many thanks to the mother of one of our participants, who recommended the "Victory Cookbook" by Marguerite Patten. It is a cookbook that was discovered at the Imperial War Museum in London. The book contains many recipes that were used during the war at a time when food was heavily rationed, making it ideal for allergic children as a lot of recipes are free from eggs and milk. Contact your local bookstore or the Imperial War Museum for further details on purchasing the book.