

Help Lucia Eat
GPO Box 3064
Brisbane, QLD 4001
07 3217 2261
lucia01@internode.on.net

3 March 2009

Dear Sir/Madam,

Lucia Belle is a three-year-old girl with a rare and life-threatening condition called Netherton Syndrome. Among the many challenges that Lucia and her family face is that **Lucia cannot eat**. This letter is to introduce you to Lucia, and to seek your financial support for Lucia and her parents to attend the one clinic in the world that will wean her off tube feeding and assist her to eat orally. This will lessen the impact of her differences and empower her to integrate more effectively with children of her own age; it will make her life much more manageable while still facing the challenges that having Netherton Syndrome presents.



Throughout her life Lucia has always attended multiple weekly appointments at the Mater Children's Hospital. Currently she attends five appointments every fortnight which are all related to the impact of her not eating and we have exhausted every avenue of relevant therapy available to us.

Due to Lucia's lack of progress in oral eating it has been suggested and encouraged by the hospital medical staff that we explore the possibility of attending a special feeding clinic in Graz, Austria. It is a unique environment which provides a holistic medical facility offering a three week intensive programme to specifically wean children off tube feeds www.kinderpsychosomatik.at/home/en or www.notube.at. They have a remarkably high success rate (95%), with some children eating orally after only two weeks into the programme. In most cases the children have a serious underlying condition and the tube-feeding has been implemented due to major hospitalisation in early infant life. We are very excited by the things we have heard about this exceptional and one-of-a-kind programme.

Therefore we are seeking a place at this clinic as soon as possible to give Lucia the best chance available to eat orally and at least have such a significant part of her life as close to other children as possible. Lucia is striving to achieve her full potential in every way and this opportunity would greatly improve her quality of life; she would benefit socially and emotionally from a skill that so many take for granted: the simple act of eating.

The hardest thing now is how we can make this happen. The cost of taking this great opportunity for Lucia is approximately AU\$30,000 – this includes return flights to Austria from Brisbane, outpatient clinic fees for Lucia, and accommodation and living expenses for the period of the programme. As Lucia's mother and full time carer, I have been unable to return to work since her birth, and coupled with the expense of Lucia's health needs with Netherton Syndrome (ointments, oils, medications, supplements, dressings, high calorie formula etc) my partner and I are under great financial strain. We have come reluctantly to the conclusion that we must seek assistance from outside our own resources if we are to achieve the success of attending this programme and giving our daughter her very best chance at eating orally.

This letter is therefore our plea for financial assistance from your organisation. We have estimated that a daily cost for clinic fees, accommodation and living expense is approximately \$760.00.

Donations can be made to Carers Queensland for the '**HelpLuciaEat**' fund – all donations are tax deductible and they can accept cheque, funds transfer and cash. Please see the attached slip for account details.

If you have any questions or require further information please do not hesitate to contact me on 07 3217 2261.

Yours appreciatively

Francesca Durnell

But why can't Lucia eat? No one can tell us for certain but we do know the following:

- Lucia was hospitalised for 6 months from birth and there is plenty of evidence to suggest that infants who experience intense 'tube' activity - through feeding via the naso-gastric and respiratory aids such as being ventilated and CPAP as Lucia experienced – are historically poor eaters due to association of pain & oesophagus distress
- Lucia was diagnosed with Eosinophilic Eosophagitis (severe inflammation of the oesophagus due to allergies) at 15months which caused her to vomit relentlessly during and after every feed for over two years
- Lucia was fed via a naso-gastric tube from birth and this was upgraded to the surgical insertion of a gastrostomy button into her stomach at 8 months of age. She has been totally dependent on this tube feeding for all her nutrition and because her condition requires a very high daily calorie intake, she is fed both bolus feeds(a set amount over a specific period of time) and overnight continuous feeding(via an electronic pump)
- Lucia has attended a 'feed clinic' at the Mater hospital weekly/fortnightly throughout her life to encourage oral intake, but the progress has been very slow. Three years on, Lucia will now lick a piece of apple, kiss a banana and pretend to nibble on a rice; while these actions are truly huge milestones they will certainly not sustain her 2000 calorie daily requirement.
- Lucia is delayed in talking as the lateral tongue movement from masticating and general oral sensations from chewing and swallowing all contribute to the development of speech.
- Lucia has weekly sessions with a child psychiatrist to try and work through her aversion to eating.

To explain Netherton Syndrome in simple term(www.scalyskin.com):

- Lucia sheds the top layer of her skin every 12 hours, which in turn leads to very red skin that looks like it is sunburnt and peeling. She does not have any body temperature control.
- This condition leads to elevated levels of sodium due to water loss and a high risk of hypernatremia.
- Lucia is extremely susceptible to infections and has a compromised immune system.
- Lucia has severe failure to thrive.
- Lucia has 'bamboo hair' (Tricorrhexis invaginata) – it is sparse and very fragile.

Lucia spent over 6 months in hospital in her first year and has endured chronic pain and many agonising procedures. The daily meticulous skincare which she must endure together with the attention to calorie intake continues to challenge Lucia's happy disposition and provide considerable challenges to her family and her whole daily routine. This complex condition has ensured that Lucia's life from birth has been full of complications, pain, extreme medical intervention and also great amounts of love and care from her family and from many medical experts.





**Queensland Council of Carers
also known as Carers Queensland**

Tel: 07 3900 8100

Camp Hill Office
15 Abbott St
Camp Hill, Q, 4152
PO Box 179
Holland Park, Q, 4121

Fax: 07 3843 1403
Email: contact@carersqld.asn.au
ABN 20 061 257 725

DONATE TO CARERS QUEENSLAND HELP LUCIA EAT APPEAL:

Name to appear on receipt (you may nominate business or individual names):

Name of Donor(s): _____

ABN: (If applicable): _____

Address: _____

Suburb: _____ State: _____ Postcode: _____

Phone (w): _____ Phone (h): _____

Phone (m) _____

Email: _____

1. Direct Credit (Bank/Internet Transfer)

Bank Name: **CBA**
Account Name: **Queensland Council of Carers Inc.**
Bank Branch: **Coorparoo BSB: 064 – 107 A/C: 10200957**

2. Cheque

Simply attach a cheque made payable to **Carers Qld** to this form and post to the above address.

3. In Person

Please phone 07 3900 8100 to obtain the address of your local office.

PLEASE ALLOCATE MY DONATION TO '**HELP LUCIA EAT**' APPEAL \$.....

Please note: On receipt of this form a tax deductible receipt will be forwarded on to the nominated donor.

Thank you for your generous support.