Research plays such a big part in future treatments, hence our dedication to be part of it and being actively involved in academic and commercial clinical trials. These are some of the studies that are running at the moment. If you want to be involved in research, however, and are not suitable for those listed below you can let Claire Adams (Specialist Nurse) or another member of the team know so we can keep you updated with any new studies.

- **Whole Genome Study** - People with Familial Partial Lipodystrophy Type 1 (FPLD1) - looking at identifying a genetic link to FPLD1.
- **Fat Oxidation Study** (part of SIR Study) - Two visits to Addenbrooke’s and a two-night stay.
- **Broaden Study** – A Phase 2/3 study administering a subcutaneous drug to patients with Partial Lipodystrophy. For any further details contact Research Nurse: Angelique.laubscher@addenbrookes.nhs.uk

If you are interested in taking part or want to find out some more information please contact Claire on: claire.adams16@nhs.net

Patient satisfaction

We send out a Patient Satisfaction questionnaire every year to new patients; last year our overall satisfaction rating was 8/10. If you would like to give feedback on the SIR service, please feel free to contact us as we are always striving to improve and all comments are noted and acted upon. We are especially keen to hear if you and/or your local healthcare team have not heard back from us regarding test results as we aim to keep you informed and would like to hear if there are any problems with getting information to you (contact details are on page 10).
March 31st was World Lipodystrophy Day. This day was started by the European Association of Lipodystrophy (AELIP) in Spain in 2012. The main objective of this campaign is to raise awareness of lipodystrophy amongst health professionals and the public across the world, and to encourage people to unite to improve care for those affected.

People are encouraged to post a picture of themselves on social media making an ‘L’ shape (for lipodystrophy) with their hands. See below for photos of some of the team getting involved in the action.

**If you have ideas on how we can promote World Lipodystrophy Day in 2017 contact Claire:** claire.adams16@nhs.net

This year **Dr. Chris Van Tulleken** (from CBBC’s Operation Ouch and BBC’s Horizon)

**Lipodystrophy Support Group Day 2017**

Following on from the success of our support group days over the last few years, we are planning another event in 2017. If you have any thoughts on what you would like to see on the agenda please let Claire (Specialist Nurse) know: claire.adams16@nhs.net
Acanthosis nigricans

Acanthosis nigricans is a velvety thickening and darkening of the skin in natural skin creases caused by severe insulin resistance. This is usually particularly marked in the neck, under the arms and in the groin, although it can sometimes be more widespread. It is not a serious condition in its own right but for some people it can be upsetting because of the effects it has on appearance.

After seeing a few people in clinic who have been distressed about the visibility of acanthosis nigricans, we spoke to the camouflage team at Changing Faces about the possibility of using camouflage make-up to cover acanthosis nigricans and they agree that this would be suitable for camouflage.

Changing Faces provide camouflage clinics in various locations all over the country (there is one here at Addenbrooke’s) and the appointments are free as they are funded by the Changing Faces charity (they encourage a small donation where possible but this is not expected). They are not able to work on broken, infectious or inflamed skin but as acanthosis nigricans is none of these things that isn’t a problem.

They offer people a one-hour appointment where they match skin colour to the camouflage and then they teach the individual how to apply it so they can do it at home themselves. Each person is given a list of recommended products which can be obtained on prescription through the GP or they can purchase themselves.

The camouflage is durable and shouldn’t come off on clothes. It isn’t advisable to cover the armpit sweat glands, but the area around the armpit that is visible could be covered, as could the back of the neck.

We can refer people or you can self-refer. This is the link:

https://www.changingfaces.org.uk/Skin-Camouflage
We are educating health care professionals nationally by raising awareness of severe insulin resistance and lipodystrophy.

**Educating health care professionals**

Raising the profile of severe insulin resistance/lipodystrophy as a clinical problem in order to improve access to optimal care for affected patients is one of our key aims. As a team we give many education sessions and lectures about lipodystrophy and severe insulin resistance.

Lipodystrophy is a rare condition characterized by partial or complete loss of subcutaneous adipose tissue and is associated with metabolic derangements including severe insulin resistance, diabetes, hypertriglyceridaemia, pancreatitis and non-alcoholic fatty liver disease. Optimal glycaemic control often requires high doses of insulin, but injections can be very painful due to lack of subcutaneous fat. At the Diabetes UK Conference this year, one of our team: Charlotte Jenkins Liu presented a very interesting poster proposing that the use of continuous subcutaneous insulin infusion therapy (CSII), insulin pump, may be a potential solution to this problem.

**Patient feedback:**
Patients attending the National Severe Insulin Resistance Service have reported an improvement in quality of life related to a “reduction in discomfort at injection sites” as well as more stable blood glucose control after starting pump therapy. In addition to this their daily insulin requirements have reduced, which we know leads to less risk of hypoglycaemia as well as reduced risk of insulin related weight gain.

Although experience is limited, insulin pump therapy appears to be a safe and effective treatment in patients with lipodystrophy. However, exceptional funding application is required before we are able to go ahead with treatment on a pump as patients in our service do not usually meet the criteria stated by NICE for pump therapy. We hope to increase the numbers of patients using pumps under the care of our service in order to gain further understanding and expertise. So if you are interested in pump therapy we would be happy to discuss this with you when you see us in clinic.
Physical Activity

Physical Activity is very important and offers massive benefits in people with severe insulin resistance/lipodystrophy both through improving insulin sensitivity as well as helping with weight management.

It can be difficult to keep up activity levels as winter draws in. The below are some suggestions to help increase your activity levels:

- If you are on a mobile phone, walk while you are on the call: this can be around the house if you are at home or if you know the call will last more than 10 or 15 minutes going out to walk while you talk
- If you are watching television, get up and walk around, or up and down the stairs during the advert breaks
- If you’re bored at home or feel fed up, a walk will give you fresh air and help keep you busy
- Go for a walk with friends – walk and talk rather than meeting in a pub or café.
- Walk or cycle to work, or get off the bus a stop early to walk
- Join a gym, or find an exercise buddy to help motivate you
- If you find the weather a barrier to exercise, consider indoor activities such as exercise DVDs or home exercises. The SIRS service have a sheet on home-based activities for more ideas so please request this from the team.
- Set yourself activity goals/targets as these can help ensure you stay motivated.
- Find something you enjoy If you enjoy an activity you are much more likely to keep up with it in the long run.
Paediatric clinic

We hope that you had a good summer and that school is going well. Why not have a go at our word search and see if you can find the mystery word, it’s got 3 letters and is furry???

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<td>Help</td>
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Blood tests

As you know we sometimes do blood tests in the clinic and we thought you might like to know why we take them, what they are called and how we use the information that these tests give us.

**HbA1c** This test tells us how much sugar has stuck to your Red blood cells in the last 3 months.

*If this result is a bit higher than normal we need to chat about how to reduce it.*
**Liver function** This test lets us know how well your liver (the largest organ inside your body) is working. The liver has lots of job to do and one of these is to make sure that extra ENERGY is stored in the right place.

*If you have a bit too much ENERGY to store, the liver struggles to put this in the right place.*

*This means test results may be higher than normal.*

**Fasting Insulin** This test needs to be taken in the morning before you eat breakfast, you can bring some food to have after the test. Your body needs to use the sugar from the food you eat and to do this your pancreas, which sits just under your liver, makes a hormone called Insulin (hormones are like messages that whizz around the body giving instructions).

**Insulin** is like a key—it opens the door in your cells to let sugar in to give you energy

*You may usually have higher than normal levels of insulin but if these are a bit too high we need to find out why this might be.*

**What happens next**

We can tell from the result how you are doing and if you are managing to eat healthily. If you are not doing so well, we can plan how to help you—this may be changing or adding medicine and we can chat about how to make healthy food choices.

**Our Plans**

- Clinic information leaflets for both parents and children available by Christmas
- An interactive tool for our younger children to use during clinic

Finding the best method for providing information to our teenage patients and any comments are very welcome. *Please email julie.harris@addenbrookes.nhs.uk*

**See you in clinic, Rachel (Dr), Julie (Nurse), Elly (Dietitian)**
News

In September we found out that we had been successful in our application for a grant to the Patients First Programme awarded by the Foundation of Nursing Studies & The Burdett Trust.

With support and guidance from the Foundation of Nursing Studies we will be developing a programme for patients to the SIR Service that will cover many aspects including building communication skills and self-esteem, how to handle other people’s reactions, questions about your condition and boosting self-confidence. The charity Changing Faces will work with us to innovate this programme, sharing material from their existing workshops. Two patient representatives from the lipodystrophy support group have agreed to be part of the team to ensure that the programme developed meets the needs of the patients.

Claire will be organising a focus group soon to get feedback, thoughts and ideas on the project from the patients in the SIR Service before we start. This will be for up to 8 people and travel will be reimbursed. If you would be interested in being involved in this, please contact Claire on claire.adams16@nhs.net.

High strength insulins

Humulin R U500 insulin (500 units/ml)

This higher concentration insulin is 500 units per ml, and is used in patients requiring very high doses of insulin. At present this insulin must be drawn up from a vial and can be quite tricky. At the American Diabetes Association Conference in New Orleans, members of the team were shown a U500 insulin Pen that is only used in America at the moment but will hopefully make its way to the UK soon! We will keep you posted...

There are some other new high strength insulins available which come in pen devices, these include background insulins degludec U200, (Tresiba) Glargine U300 (Toujeo) and the short acting insulin Humalog U200. Please contact us if you would like any information on these insulins. NB: access to these insulins still varies across the UK and depends on the local CCG pharmacy committee decision to fund them, however their use is becoming more widespread.
How low can you go?

Including small, low fat and low carbohydrate snacks can be helpful with motivation when following a healthy diet. Below are some suggestions of suitable snacks. If you have found any other good snack ideas, please share these with us:
email lisa.gaff@addenbrookes.nhs.uk

Snacks with up to 15g carbohydrates or fewer:

<table>
<thead>
<tr>
<th>Snack</th>
<th>Portion Size</th>
<th>Calories (kcal)</th>
<th>Carbohydrate (g)</th>
<th>Fat (g)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 medium apple or pear</td>
<td>120g</td>
<td>60-65</td>
<td>15</td>
<td>0</td>
</tr>
<tr>
<td>Blueberries, cherries or blackberries</td>
<td>100g</td>
<td>50</td>
<td>12</td>
<td>0</td>
</tr>
<tr>
<td>Banana</td>
<td>1 (fun sized)</td>
<td>50</td>
<td>15</td>
<td>1.5</td>
</tr>
<tr>
<td>Nice biscuits</td>
<td>2 biscuits</td>
<td>78</td>
<td>10</td>
<td>4</td>
</tr>
<tr>
<td>Ginger nut biscuits</td>
<td>2 biscuits</td>
<td>88</td>
<td>16</td>
<td>2</td>
</tr>
<tr>
<td>Rich tea biscuits</td>
<td>2 biscuits</td>
<td>64</td>
<td>10</td>
<td>2</td>
</tr>
<tr>
<td>Pineapple tinned in fruit juice (exclude juice)</td>
<td>3 rings</td>
<td>49</td>
<td>12</td>
<td>0</td>
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<tr>
<td>Kiwi fruit</td>
<td>2</td>
<td>48</td>
<td>10</td>
<td>0</td>
</tr>
<tr>
<td>Strawberries (small)</td>
<td>14</td>
<td>50</td>
<td>10</td>
<td>0</td>
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<tr>
<td>Grapes</td>
<td>10</td>
<td>40</td>
<td>10</td>
<td>0</td>
</tr>
<tr>
<td>Grapefruit</td>
<td>1/2</td>
<td>24</td>
<td>5</td>
<td>0</td>
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<tr>
<td>Whole fresh apricots</td>
<td>3</td>
<td>50</td>
<td>12</td>
<td>0</td>
</tr>
<tr>
<td>Melon</td>
<td>150 grams</td>
<td>50</td>
<td>10</td>
<td>0</td>
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<tr>
<td>Nectarine</td>
<td>Medium</td>
<td>66</td>
<td>15</td>
<td>0</td>
</tr>
<tr>
<td>Clementines</td>
<td>2 small</td>
<td>44</td>
<td>10</td>
<td>0</td>
</tr>
<tr>
<td>Bread sticks with salsa</td>
<td>2</td>
<td>40</td>
<td>8</td>
<td>0</td>
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<tr>
<td>Pretzels</td>
<td>15 grams</td>
<td>50</td>
<td>10</td>
<td>0</td>
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<tr>
<td>Chocolate Extra Light/ Skinny Cow®</td>
<td>1 sachet</td>
<td>Up to 120Kcals</td>
<td>Less than 10</td>
<td>Up to 4 g fat</td>
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<tr>
<td>Low fat/ diet yoghurt</td>
<td>Varying 120-125g</td>
<td>58-74Kcals</td>
<td>8.5-11</td>
<td>0.2 or less</td>
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<tr>
<td>Sugar free jelly</td>
<td>1 pot</td>
<td>Less than 10</td>
<td>Less than 1</td>
<td>0</td>
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<tr>
<td>Popped corn (no added butter or sugar)</td>
<td>20g</td>
<td>60</td>
<td>5</td>
<td>4</td>
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<tr>
<td>Ryvita / crisp bread / oatmeal cracker</td>
<td>1</td>
<td>18-78</td>
<td>4-8</td>
<td>2</td>
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<tr>
<td>Sushi</td>
<td>1 piece</td>
<td>40-60</td>
<td>6-10</td>
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</table>
Hi Everyone,

I just wanted to share with you a couple of insights I gained at the Appearance Matters Conference in London in June. As many of you know I am doing some research looking at how lipo-dystrophy affects body image so this conference was a good opportunity for me to learn a bit more about body image on a wider scale.

The conference was hosted by the Centre of Appearance Research (part of the University of the West of England in Bristol) at the Royal College of Surgeons. This is the link to their website if you would like to find out more about them:

http://www1.uwe.ac.uk/hls/research/appearanceresearch

This wasn't a clinical conference and it covered everything from visible differences in low income countries to beauty and the media.

Something that people might be interested in is the Dove Self Esteem Project:

http://selfesteem.dove.co.uk/Articles/Written/What_is_body_confidence.aspx

This is a free online resource that is aimed at women and young girls.

There were discussions around interventions for people with negative body image due to a visible difference and there is a lot of evidence to say that group work in this setting is beneficial. Something else that was said is that the severity of the visible difference does not necessarily equate to the negativity a person experiences - for example someone could be very distressed by a small blemish on their arm, while someone else could have a much more obvious difference and not be distressed.

The one session however that really struck a chord with me was: "I've always thought that I'm not good enough... why would someone be with me: A qualitative exploration of the impact of visible difference upon intimacy and intimate relationships". This session was focused around cleft lip, and how people felt very self conscious of their appearance when they were with a new partner but it also covered the anxiety around kissing someone new as for cleft lip this is a functional issue too. I came away from this session thinking that this is an area that we don't really cover that much in lipodystrophy and actually this is something that we could improve on. I'd be interested to know people's thoughts on this.

If anyone has any questions please feel free to ask me - you can contact me on claire.adams16@nhs.net

Thanks!
Claire
A fantastic effort from Ian Erentz and Stephanie Hetley who both completed the Great South Run and raised £650 for CLIMB, an organisation which provides advice, information and support to families and professionals affected by metabolic diseases.

And it’s not too late to donate! The Just Giving site is still active: [https://www.justgiving.com/fundraising/Steph-Hetley](https://www.justgiving.com/fundraising/Steph-Hetley)

New members of the Cambridge team:

A warm welcome to:

Audrey Melvin,
Clinical Research Fellow, who will be doing some work on the impact of bariatric surgery on lipodystrophy

and

Angelique Laubscher,
Research Nurse

Congratulations!

And welcome back from maternity leave for dietitians Catherine Flanagan (adults) after the birth of her twin girls and also to Fliss Pollendine (paediatrics) after the birth of her baby daughter.
Websites and telephone support

It is not uncommon for people managing long-term medical conditions to feel low in mood, anxious or depressed. The following websites offer different support, guiding you with techniques to help you manage daily stresses. If you feel that face to face mental health support/counselling would be better for you, please speak to your GP or the team and we can help you with a referral for this.

**Samaritans**
Confidential support for people experiencing feelings of distress or despair.
Phone: 08457 90 90 90 (24-hour helpline)
Website: [www.samaritans.org.uk](http://www.samaritans.org.uk)

**Depression Alliance**
Charity for sufferers of depression. Has a network of self-help groups.

A selection of websites for web based support:

**NHS Choices**

**E couch**
[https://ecouch.anu.edu.au/new_users/welcome01](https://ecouch.anu.edu.au/new_users/welcome01)

**Mood gym**

**Mood juice**

**Get self help**
[http://getselfhelp.co.uk/](http://getselfhelp.co.uk/)

Help Needed!

Lipodystrophy UK are looking for some (free) help designing their logo. If you have the skills and think you might be able to help, please contact Claire and she will pass on to the team. Email claire.adams16@nhs.net or 01223 768625
Useful links

If you want to find out a bit more about living with lipodystrophy or connect with people online, there are support groups and Facebook pages available.

**Websites**

- [http://www.lipodystrophy.co.uk/](http://www.lipodystrophy.co.uk/) (UK)
- [http://www.lipodystrophyunited.org/](http://www.lipodystrophyunited.org/) (USA)
- [https://www.changingfaces.org.uk](https://www.changingfaces.org.uk) (UK)

**Facebook**

- UK Lipodystrophy Support Group - Lipodystrophy UK
- US Lipodystrophy Support Group - Lipodystrophy United
- Living with Familial Partial Lipodystrophy (FPLD)
- Welcome to the group Congenital Generalized Lipodystrophy!
- Changing Faces

**Twitter**

- Lipodystrophy United — @andra_LU (President and Co-Founder of Lipodystrophy United)
- Changing Faces — @FaceEquality

Please stay in touch

We know you have your local teams and encourage you to work with them as much as possible but please do contact any of us if you would like support in between appointments. Our details are on all the patient information sheets we give you but you can also contact us on the telephone numbers / email /

**National Severe Insulin Resistance Service**

Institute of Metabolic Science
Box 289 Addenbrooke’s Hospital, Hills Road
Cambridge CB2 0QQ

**SIRS main office tel:** 01223 768455
**SIRS appointments:** Kristie Bagstaff 01223 348123
**Email:** insulinresistance@addenbrookes.nhs.uk

NB: If you have any concerns that you don’t wish to share directly with us, you can also contact the Patient Advice and Liaison Service (PALS) based in the hospital on 01223 216756.