



The 2016 DBA UK Family Weekend
Friday 20th – Sunday 22nd May

PGL centre, Caythorpe Court, Caythorpe Heath Lane, Caythorpe, Grantham, Lincs, NG32 3ER

The 2016 DBA UK Family Weekend is your chance to meet others affected by DBA and share experiences, hear more about DBA from medical professionals, and to keep in touch with what the charity is up to.

Here is a google maps link to the location - <https://goo.gl/maps/mNb97b3qPTq>

The accommodation will again be in the wooden chalets we have had in previous years and each family will get their own room. One thing to remind you is to bring towels with you and as the bathrooms are all wet rooms, you will need to bring your own baby bath if required, and also a highchair but everything else, including food is provided. The accommodation *is* quite basic, but we've had adequate feedback on it in previous years.

Planning is still underway, but we can detail that in this year's conference we have:

- Presentations from medical experts
- 1-on-1 clinics with medical experts
- Ample opportunity to speak with each other, both formally and informally
- Specific sessions and activities for adult DBA patients (suggestions welcome)
- BBQ and campfire (including sing-songs) for all
- PGL adventures for the kids (high-wires, quad-bikes, archery and so on)
- The DBA UK AGM and charity report 2016

The DBA UK Charity Annual General Meeting will be held on Sunday 22nd May as part of the Conference. This includes a report on what the charity has been up to and there is an opportunity to elect a Committee for the following year. New blood is really encouraged on the committee. Anyone with interest and a special skill to offer can speak with the DBA UK Chairman (Leisa Batkin), Deputy Chair (Jayson Whitaker) or any other committee members for a discrete chat to find out more. The constitution requires that nominations for election to the Executive Committee are received in writing by the Secretary 14 days prior to the AGM.

You can arrive at Caythorpe Court any time after 3pm on Friday 20th May for games and fun and to start to meet people. The conference sessions will then start before 9am on the Saturday, with coffee breaks and lunch. The conference will end after lunch on the Sunday. There is ample parking for all.

As ever, please bring with you any questions you have. It would also be greatly appreciated if you could bring any DBA paraphernalia such as pumps, needles, drugs and other treatments to show around and help us learn from each other.

Please also be sure to bring any unused or surplus fundraising equipment/merchandise and collection boxes (full or otherwise) which can be passed to our Fundraising Co-ordinator Martin Winter and Treasurer Peter Redmond respectively.

Please don't forget about our private Facebook group where you can ask questions of other DBA families before the conference, it can be found here - <https://www.facebook.com/groups/85069525487/>

If you would prefer external accommodation and to head on to the site each day this is fine, but DBA UK will not be able to cover the hotel costs and you will need to book this yourself -

This is the nearest Travelodge (6 miles away) -
<http://www.travelodge.co.uk/hotels/177/Sleaford-hotel>

And here is a B&B located nearby (under 1 mile away) -
<http://www.waggonandhorsescaythorpe.co.uk/>

We're really excited about this year's 16th Anniversary Family Weekend and hope as many of you can join us as possible, places go fast so please book sooner rather than later!

Completed booking forms (below) must be emailed or posted to [Kieran Teasdale, DBA UK secretary](#).

Useful Web Addresses

DBA UK Website - <http://diamondblackfan.org.uk/>

DBA UK Facebook Page (public) - <https://www.facebook.com/dba.org.uk>

DBA UK Facebook Group (private) - <https://www.facebook.com/groups/85069525487/>

DBA UK Twitter - https://twitter.com/DBA_UK

Directions to Caythorpe Court PGL Centre

Travelling South on the A1.

At the A46/A17 junction (Newark on Trent) take the A17 for approx 10 miles then turn right onto Pottergate Road.

Follow this for 1.5 miles then turn right onto Caythorpe Heath Lane.

The Centre is on the left after approx 1/2 mile.

Travelling North on the M1.

Take junction 21A for the A46. Follow this to Newark (do not take the A607 off the A46 as this is a slow windy road through lots of little villages).

At Newark take the A17 and follow directions as above.

From the North-West

Take the M62 to the A1, then head south as above.

From the South-West / Midlands

Take the M42/A42 until it joins the M1.

At Junction 25 take the A52 towards Grantham.

Take the A46 towards Newark.

At Newark take the A17 and follow directions as above.

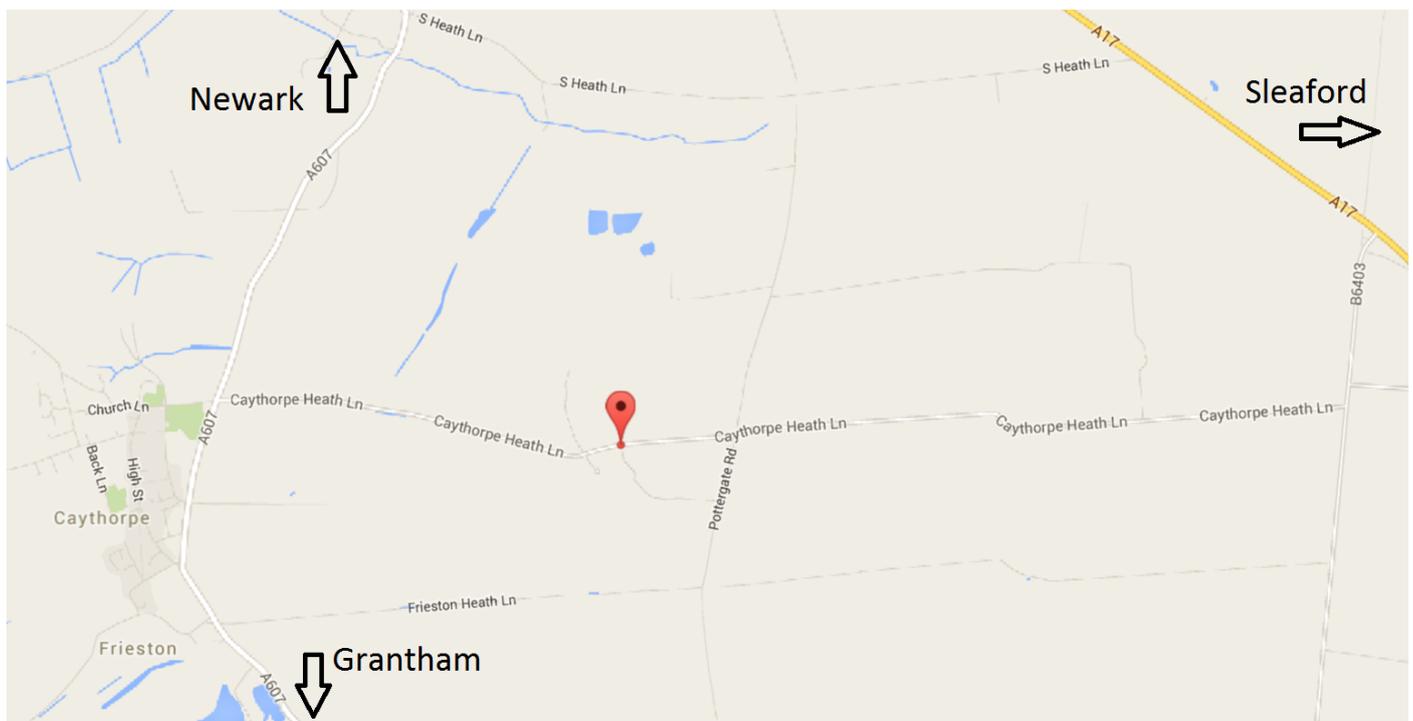
Travelling North on the A1

At Grantham take the A607. Watch out just north of Barkston where you have to take a left turn to stay on the A607.

At Caythorpe turn right onto the Caythorpe Heath Lane.

The Centre is on the right after approx 1 mile.

Nearest airport is East Midlands airport (though not too close). Please say if you are likely to take this route as we may be able to find groups willing to travel together to reduce your costs.

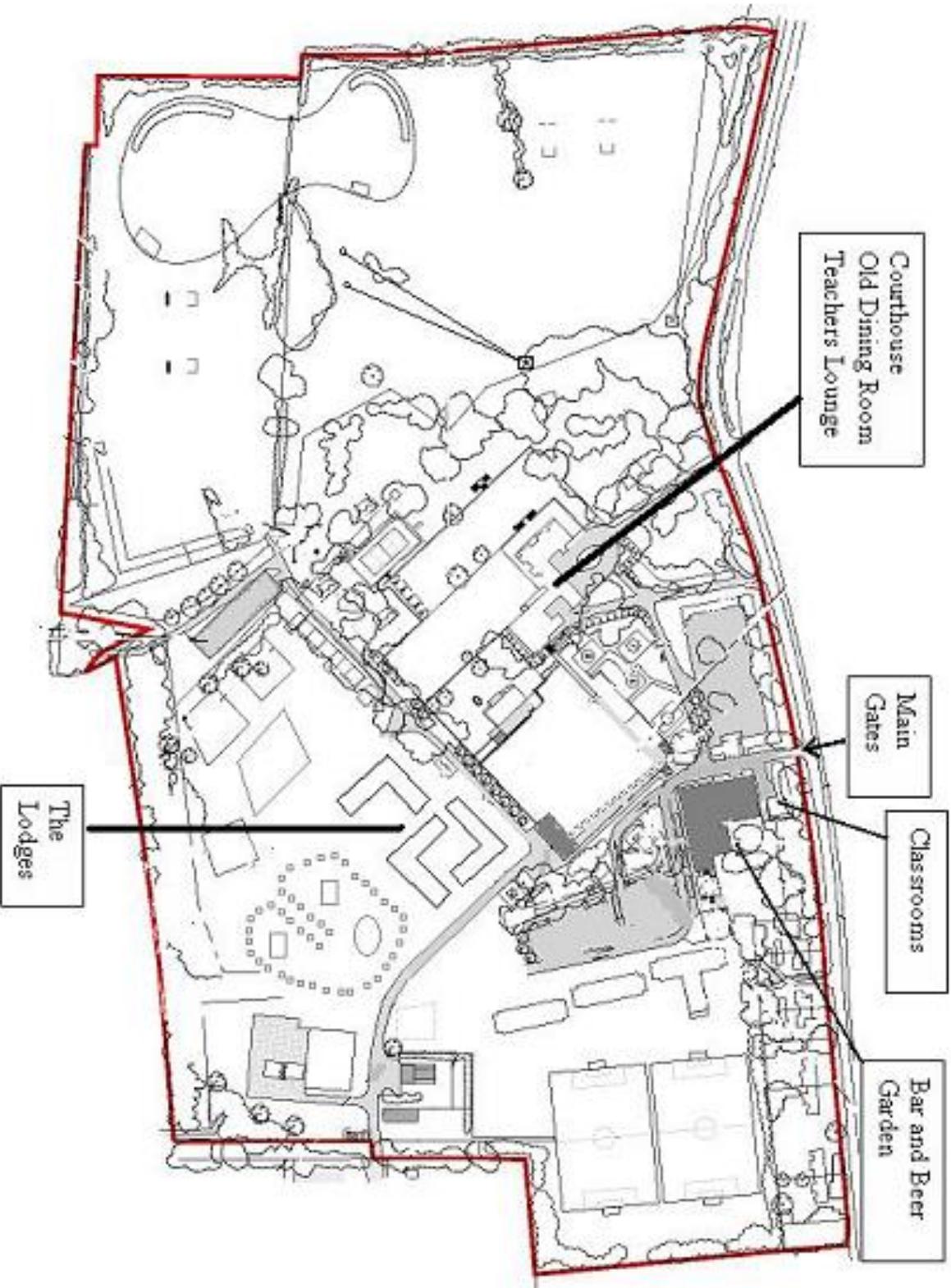


Below is a picture of the PGL entrance gates, for you to be sure you are at the right place!





Caythorpe Court





Family Weekend 2016
 PGL at; Caythorpe Court, Caythorpe, Grantham, Lincolnshire, NG32 3ER
 Friday 20th to Sunday 22nd May 2016

Booking Form

Name		
Address		
Telephone numbers		
Email address		
DBA Connection		
Any special requests (e.g. accommodation; dietary)		
Names of all attendees		Age (if under 18)

The annual conference is a significant cost to DBA UK: over £120 per person which is over £10,000 for the whole event. We'd like each person coming to try to donate something back, and would suggest at least £20 per person although we'd be happy to receive anything closer to the full cost if you are able. Cheques can be passed to Treasurer Peter Redmond during the Family Weekend. These donations are not obligatory, however, and we're primarily keen to get as many DBA UK members to the Conference as possible. If you feel you are unable to contribute then please just bring yourselves and prepare for what should be a fun, interesting and rewarding weekend for all.

Please send this completed page to: Kieran Teasdale, Secretary, DBA UK
60 Highland Drive, Loughborough, LE11 2HU

Or email to - secretary@diamondblackfan.org.uk

Any questions? Ring Kieran on 07919 072976

Photographs are often taken during the weekend, which may subsequently be used on our DBA UK website and social feeds, if you would rather your child was not used in any published photographs, please tick this box.

DBA UK Committee

The charity is managed by an Executive Committee, as follows as elected at the May 2015 AGM.



Leisa Batkin, Chair

I am 42 and I live in Leeds with my husband and our 4 children. Our youngest, Christie is 4 and was diagnosed with DBA when she was 3 months old. She is currently on regular blood transfusions and chelation therapy.

I have joined the committee to help and support other families and have an interest in social welfare of our families and work in Health.



Jayson Whitaker, Deputy Chair

I am one of the founder members of the charity and current support group. My son Charlie age 17 had transfusion dependent DBA, he had a transplant which failed after 10 years, so has had a second transplant 2 years ago. I have 3 other children who do not have DBA, I have been involved in DBA UK for about 16 years, my wife Michelle is actively involved in the conference organisation each year and has been for many years.



Peter Redmond, Treasurer

I live in Jersey with my wife Trish and two children Joe and Holly. Joe is 6 years old and has DBA. He was transfusion dependent and did not respond to steroids. Amazingly Holly was a perfect match for Joe so last year he had a very successful Bone Marrow Transplant.



Kieran Teasdale, Secretary

I live in Loughborough, I'm 33 and I'm married to Hayley, who has DBA. I've been to a few of the annual conferences now and wanted to help with the running of the charity and website.



Martin Winter, Fundraising Co-ordinator

I live in Billericay, Essex with my wife Sarah and daughter Olivia. Olivia was conceived via IVF in 2010 and diagnosed with DBA at 6 weeks of age, following a failure to "thrive". Olivia remains transfusion dependent (every 4 weeks) as she did not respond to steroids. We are currently investigating the feasibility of a Bone Marrow Transplant for Olivia. I have joined the committee to help provide continued support and hope to Olivia and our wider DBA family. My role will focus on fund raising co-ordination.



June Kynoch, Fundraising Support

I live in Chester le Street Co Durham with my husband Dave. I am a Business Admin Assessor for East Durham and Houghall College. My hobbies are Cross stitch, hand making greetings cards and the best of all is cycling. Organise the Coast to Coast bike ride to raise funds for DBA. I am the Nanna to Charlie Whitaker who was diagnosed with DBA when he was 12 weeks old.



Hayley Teasdale, Adult Patient Liaison

I wasn't diagnosed with DBA until I was 20 years old, which is unusual with DBA. I am now 30 and have blood transfusions every 6 weeks, and take Exjade daily to prevent iron overload. In 2012 I organised the first get together specifically for adult DBA patients, since then I have been part of the DBA UK committee for the past 3 years, securing my role as adult patient liaison.



Sam Robinson, Fundraising Support

I live in Farnborough Hampshire with my husband and 5 children. Our youngest, Reagan, was born in Jan 2010 and diagnosed with DBA at 7 months old. Reagan began her steroid trial just before her 2nd birthday and has remained on them and transfusion free ever since.



Helen Till, Education and Welfare Support

I live just outside Chester, in the North West of England, with my husband and two children. Lexie is 11 and DBA free, Drew aged 4 has DBA and was transfusion dependant (with 24/7 IV desferal chelation) until June 2014 when he underwent a bone marrow transplant at RMCH with his sister as a donor. I have a personal interest in education, especially the transition from pre-school to reception and I have a good overview of primary education and SEN through my role as a school governor for the past 4 years.



Stacey Skepper, Fundraising Support

I am from Lincoln, I'm 24 years old. I was diagnosed with DBA just before my 3rd birthday. I responded to steroids up until the age of 19. The steroids stopped working last year and I am now transfusion dependant and take exjade daily. I'm currently working in London as a nanny.



James Dent, Adult Welfare and Employment Support

I live in Southbourne on the south coast. I'm 34 years old and was diagnosed with DBA at 18 months. Currently steroid dependent, I joined the committee to help support new families and adult patients while working as a Marketing Manager.



Paul Hubbard, Fundraising Support

I live in Redcar with my wife Joanne and three children Jack, William and Ruby. Ruby, 4 year old has DBA and was diagnosed at six weeks. Ruby is blood transfusion dependent, every four weeks and takes Exjade for iron chelation. Ruby had a steroid trial but failed to respond to steroids.