

EAST OF ENGLAND CHILDREN AND YOUNG ADULT'S DIABETES FAMILY SUPPORT NETWORK

Annual Report 2024



Charity Number: 1200362

The charity exists to support children and young adults with diabetes in the East England through the provision of education and support services such as adventure camps, activity days and support groups for the young people and their families.



Figure 1: Map of the East of England Children and Young Adults's Diabetes Family Support Network area.

Introduction

The annual report is a chance to celebrate the hard work of the East of England Children and Young Adult's Diabetes Family Support Network, to highlight the good work of both the charity and the people that volunteer within it.

There has continued to be a lot of excitement within the children and young people's diabetes community as the number of children who have been able to access hybrid closed loop technology has increase rapidly in line with the NICE technology appraisal. The support network was able to support this role out with the organisation of an education day about hybrid closed loop technology for patients and their families. This was very well attended and the feedback from the families was excellent. Many left the event feeling more confident about their ability to use the technology and more certain about the system that they wished to choose for their young person.

The support network was also able to help facilitate training events for diabetes health care professionals to ensure that they were up to speed with the new technology and felt confident to be able to support families as they were initiated on the systems.

The support network prides itself on the wide range of engagement activities that we can offer to children and young people with diabetes and their families. This year these have included:

1. 3 diabetes adventure camps for children and young people of different age ranges
2. A ski trip for 18 young people to Andorra supported by a team of diabetes health care professional volunteers
3. A trampoline park event where young people could have fun on the trampolines while their parents learnt more about diabetes technology at a teaching session
4. A Christmas party for our younger children and their families where they got to meet new friends and have a visit from Father Christmas
5. A day at a water park where the young people got to learn how to paddle board and had great fun on the lake's inflatables
6. A bowling and pizza event for kids with diabetes and their dads
7. The 6th East of England Diabetes Games which was attended by over 500 people from across the region

We are very lucky that we have a team of dedicated diabetes health care volunteers from across the region who are happy to give up their time to volunteer at these events to make sure that they are a success and that families feel safe and supported throughout the activities.

The East of England is the only region in the country that has a charity like this that can provide support and organise engagement events for the young people and their families outside of the hospital environment. We regularly receive feedback from families telling us how much they value the opportunities that we provide for them to meet other families with diabetes and how important it is for the young people to receive support like this outside of the clinical environment.

Since we set up our diabetes camps in 2013, we have seen over 900 children and young people benefit from the opportunities that these camps give them to make new friends and to try different adventure activities and to learn to become more independent in the management of their diabetes in a safe and supported environment. We are now seeing kids who first came on camp when they were 8 turn 18 and remaining close to the friends their made on their first diabetes camp. Friendships like these are amazing as they provide the young people with peer support from people who totally understand what it is like to live through the highs and lows of growing up with diabetes.

Over the coming year we plan work even harder as a charity to provide more support events and activities that are accessible and inclusive to all children and young people in the East of England with Diabetes and their families.

Matt Williams
Network Chair – April 2025

Background

The East of England Children and Young Adult's Diabetes Family Support Network was set up and registered with the Charity Commission in 2022 to work alongside The East of England Children and Young People's Diabetes Network to support the work of the diabetes network and to provide peer/family support, education (both formal and informal) and fun activities for children, young adults and their parents or carers. The support network is managed by six trustees (listed below)

Trustee	Role
Matthew Williams	Chair
Claire Moon	Treasurer
Kate Wilson	Secretary
Tracy Assari	Trustee
Jane Baillie	Trustee
Paula Olsen	Trustee

The work of The East of England Children and Young Adult's Diabetes Family Support Network is reported on at every meeting of The East of England Children and Young People's Diabetes Network, with the trustees meeting four times a year via Microsoft Teams.

We have a Facebook page (Parents Support Network – for East of England Paediatric Diabetes) for families from across the region which currently has over 1300 members. We use this page to advertise support network events to families and to seek their opinion on service developments and future events and projects that we might wish to organise and deliver. We encourage all regional diabetes units to tell families about the work of the support network and to advertise our events to their caseloads.

Education

Facilitating and delivering education for diabetes health care professionals, patients and their families forms a huge part of the work of the support network.

In 2024 these have included:

1. An introduction to diabetes technology day for health care professionals that are new to working in the field of diabetes.
2. A technology masterclass for health care professionals that have worked in diabetes for a while.
3. A Technology teaching day for patients and families held in Swavesey.

For 2025 we have the following study days in the pipeline:

1. A session for parents on how they communicate with their young people about sex, relationships, drugs and alcohol
2. Another technology education day for families to focus on hybrid closed loop systems.
3. A study day for families on the opportunities we have to get involved in diabetes research in the East of England.

Diabetes Adventure Camps

When we started our network diabetes adventure camps in 2013 we had no idea quite how popular they would become. Initially we thought we might have enough demand to run one every other year. However, demand is now so great that we run 3 camps a year for the 3 different age bands: 8- 10 years of age; 11-13 years of age; 14+ age group.

Each year we have up to 75 children across all three age ranges attend the camps. Over the course of the weekend the young people make new friends, try new activities and learn how to become more independent with the management of their diabetes. Our amazing team of volunteers support them through this process while also educating themselves about what it is really like to live with diabetes 24/7.

We would like to take this opportunity to say a huge thank you to all our volunteers who give up their weekends to make these camps happen. They would not be possible without you, and the experience that you help to bring to our young people is invaluable.

Our camps continue to be incredibly popular with spaces selling out within days of going on sale. We make sure to offer priority booking to those who have not attended before as we want as many young people as possible to benefit from the diabetes camp experience.

This year we have worked with the East of England Children and Young People's Diabetes Network to carry out a retrospective audit and review of the camps. We asked the young people and their families to fill in questionnaires to tell us what they thought about the camps. We also asked our staff volunteers to complete a survey to tell us what they had gained from their experience of volunteering on the camps. The results of this review have been very encouraging, and we will work together with the clinical network to publish them in 2025.



Network Family Events 2024

The main feedback that we receive from families is that having a diagnosis of diabetes makes them feel very isolated and alone. They are very keen to have opportunities to meet with other families living with diabetes so that they can make new friends and build a support network of like-minded people who can support them to navigate life with diabetes.

For this reason we try to organize a wide range of activities that enable families to come together to meet each other and to feel that they are not alone.

In 2024 we have held:

1. The diabetes games which took place in Bury St Edmunds in July and was attended by over 500 people from across the region
2. An education day at a trampoline park attended by over 100 young people with diabetes

3. A bowling event for type 2 patients in Luton
4. A glo golf event for type 2 patients in Peterborough
5. 3 diabetes camps
6. A network ski trip to Andorra
7. A fundraising hike on Hadrian's Wall
8. A Christmas party for our younger patients and their families
9. A water sports day at Lake Ashmore
10. A bowling and pizza event for the young people and their Dads



All of these events have received very positive feedback with families very keen for us to organize even more events in the future.

This year was the first time that we organized events specifically targeted at children and young people with Type 2 diabetes. These events were not very well attended – but the young people who did event reported that they enjoyed the activities and would be keen to come again.

We then carried out a survey of all type 2 patients in the region to find out whether they would like to come to events in the future, and if so what type of events they would like us to arrange. We also asked them if they didn't want to come to events what their reasons were.

We will use their feedback when looking to plan further type 2 events in the future.



Cape Town Diabetes Partnership Project

In the summer of 2024, we started the recruitment process for the next phase of our Cape Town Diabetes Partnership Project.

We have selected 11 young people with diabetes and 10 diabetes health care professionals from across the region to join the team that will be travelling to Cape Town at Easter 2026.

We have had a number of team planning sessions where the team have been able to get to know each other and to discuss and plan what the project will look like.

In Cape Town the young people will join 60 children and young people with diabetes who live in the Cape Flats, on a diabetes camp. On the camp they will learn more about diabetes as well as having the opportunity to try out new activities together and to learn more about each other's culture.

They will also be participating in a sports and wellness project in one of the townships outside of the city. Fundraising for the project is already underway with the young people raising money through quiz nights, concerts, bake sales, car washes and many other activities.

We are all very excited about the opportunities that lie ahead for us a project team as we move into the next stages of planning.

Matt Williams, Kate Wilson and Jane Baillie— co-leads of the Cape Town Diabetes Partnership Project 2026



East of England Mobile Phone Project

A big focus nationally within the CYP diabetes community this year is on how services that are delivered to all families with diabetes living in England and Wales can be 'poverty proofed'. We know that children with diabetes who live in poverty are far more likely to experience poor diabetes outcomes than their more affluent counterparts. This is reflected in the low levels of diabetes technology take up in the poorest centiles within society.

The North-East Children and Young People's Diabetes Network have been working with a local charity to look at what can be done to better support these families. From the work they have done together they have come up with the concept of 'poverty proofing' the care that we deliver to all our children and young people with diabetes.

From this work they found out that one of the biggest barriers that these families faced when they were offered CGM, pumps and HCL was the fact that they could not afford a mobile phone (a device which many of the systems on the market require the family to have) or any device through which they could upload their child's diabetes data.

They have set up a recycled technology project across the North-East and Cumbria through which one NHS trust passes on mobile phones and tablets from the trust when they have reached the end of their 3-year period of usage. These phones are then totally reset and refurbished and delivered to a local diabetes charity. Teams can refer families who are in need of a mobile phone to support diabetes management to this charity and the charity will then provide the family with a suitable mobile phone. The project has been able to access free sim cards from vodaphone. These are loaded into the mobile phones before they are given to the family. If needed a family worker from the charity will support the family to set up the phone and make sure that they know how to use the diabetes management apps that they need access.

Jenny Foster from the North-East presented this project to the East of England Children and Young People's Diabetes Network steering group meeting. The discussion that followed her presentation led to the

conclusion that we really need a similar service in the East of England. We have been having meetings with various people to look at how such a service would work in our region.

Discussions are underway as to what a similar project would look like in the East of England. It is felt that this is a piece of work where the family support network will be best placed to take the lead. Therefore, we are currently in negotiations with potential funders and technology providers to discuss what the next steps will be.

As soon as the project is ready to launch, we will share publicity and referral information with the regional clinics.

Fundraising

One of the top priorities for us as a charity is to make sure that the services that we provide such as our camps and our activity days are accessible to all regardless of their financial circumstances.

We have worked very hard to make sure that we are able to provide free places at these events for those who would not otherwise be able to afford to attend.

In order to do this we need to make sure that we have the funds available to pay for these subsidised places.

For the past 4 years the money to do this has been raised through annual fundraising hikes, where families and health care professionals from across the region have come together to take on hiking challenges across the country to raise as much money as possible for the support network. So far, we have taken on the three peaks over three years and raised £30k for the charity in the process.

This year we took on our first ever 2 day hiking challenge along the iconic Hadrian's Wall. 30 walkers took on the challenge through some very challenging weather to raise £7k for the charity.

We would like to thank the walkers and all those who sponsored them for their support.





Accounts

The network uses Barclays Bank, the details of which are registered with The Charity Commission. With accounting services provided by Hannah Elsom Consulting (35 Glover Street, Over, Cambridge, CB24 5PQ). Our accounts can be viewed by opening the links below:



2024
profit_and_loss_2025

These have been reviewed and certified by the charity chair and treasurer:

This is to confirm that we are happy with the supplied documentation of financial history as trustees of **THE EAST OF ENGLAND CHILDREN AND YOUNG ADULT'S DIABETES FAMILY SUPPORT NETWORK**
Charity Number: 1200362 given to us on 19/09/2025.



Claire Lynn Moon
Treasurer



Matthew Williams
Chair

As of 31st December 2024 our bank account balance was **£41,074.20** with the majority of the income coming from ticket sales for events (e.g. camps, ski trip and South Africa 2026 fundraising) and the Hadrian's Wall Walk, with most of the expenditure going towards the camps, ski trips and additional items e.g. snacks required for these.

Thank you

We would like to say a huge thank you to everyone who has supported the work of the network this year and made all of the achievements highlighted in this report possible.

Thank you to everyone who attended any of our network events both in person and virtually over the last year. These would not be possible without the input of all members of the network who work together and support us so brilliantly in all that we do.

'If you want to go fast; go alone. If you want to go far; go together'