Registered charity number 1175812

Charity status received on 20 November 2017

CADASIL Support UK

Website and Facebook

www.cadasilsupportuk.co.uk

- The website has been built and it has tried to be
  - Easy to navigate
  - Easy to read
  - Easy to find
  - Informative

- The website is also linked to Twitter so that any news and updates can go straight on for things like conferences, news and updates etc

Useful links and contacts

- On the above page there are links to other websites that people have found useful
- There is also a PDF version of the medical card which was discussed last year. You can print that and put it in your purse or wallet, or order a laminated copy for £1 plus postage
- On each page of the website there is a link to the Facebook group which takes you direct to there
- There is also a downloads section where you can download various literature from. This also includes the notes from last years conference all sent to us by Jessica Walsh
- This also has the live Twitter feed on it for news and updates

Fundraising

- We have already held two fundraising events
- One was to eat as many crème eggs as possible in 20 minutes live on Facebook an that raised £350
- The other was the longest zip wire in Europe and that raised an amazing £1,759.04

- The money we are all going to raise will be for flyers and brochures etc to help raise awareness for CADASIL – get people talking about it in doctors waiting rooms
- We have a paypal, the charity bank account, my donate and Amazon Smile all set up ready to go.

CADASIL affects people in different ways so we felt it would be an idea to share some real life stories on the website from either people that have been diagnosed with the disease or members of the family that also live with it.

If you would like to share your experience of living with CADASIL, pleas

Life stories – whether you're a patient or carer

- We did a post on Facebook asking for people to tell their story
- Irena contacted people and managed to get a few volunteers to talk about how they are dealing with CADASIL
- We think when you are first diagnosed you have no clue what is going to happen, but if there were actual real life stories told by people living with CADASIL or that are living with someone that has it, it may help them


Glenn's story

CADASIL SUPPORT UK
#DefyTheOdds

Home Get support Life stories Useful links and contact

, 62 , from Bressingham near Diss in Norfolk, UK

adline: "Having Cadasil has drawn my wife and myself closer"

I first found out I had Cadasil after I had a stroke, the scans were not what the neurologist expected, so he called in a consultant neurologist from Addenbrookes in Cambridge, UK.

When I first left hospital I had problems with walking, balance and anxiety, it felt like I was going home to die. When I received the Cadasil diagnosis I was devastated.

Having a stroke changed everything in my life, like I had to relearn everything. I couldn't drive, and I felt my life was over.

Now, in some ways I feel like Cadasil has enriched my life, which sounds stupid I know.

It has allowed me an opportunity to do something worthwhile by raising awareness about the condition. It has allowed me to see what things are important and what's not worthwhile and perhaps you see a beauty in life which wasn't there as you don't take life for granted.

Having Cadasil has drawn my wife and myself closer, we were always close but we know the time together may be shorter than expected as I'm not going to live to be a hundred. I also found out very quickly who my true friends were, and removed any toxic people from my life.

In terms of relatives with Cadasil, I don't know of any, as I was adopted and have no children of my own.

At work, I found that Cadasil did have an impact too. I had problems with my manager, although I was the top performing Health Safety and Environmental Manager in the company, he targeted me, so I took early retirement.

On the whole the medical professionals treating me have been fantastic, my local doctors have been supportive and taken the trouble to learn about the condition. Addenbrookes are just fantastic.

The biggest supports to me have been my wife, doctors and neurologists and friends who have been there for me.

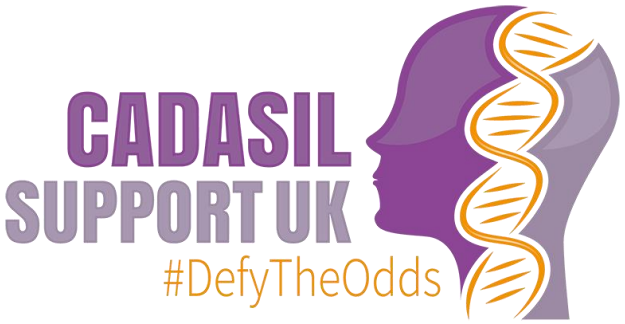
My biggest hope for the future is to stay well enough to keep raising awareness and keep a good quality of life. But most of all to be a good husband so she has really good memories when I'm no longer here.

The best advice I was given was by a terminally ill man when I was struggling with my diagnosis "whilst you are busy dying don't forget to live", these words changed my life. From this I started to run, raise awareness, got interested in things again, love life, I'm very lucky.

Cadasil Support UK Charity Number: 1175812 Charity registered address 110 Heathmoor Park Road Halifax HX2 9LP

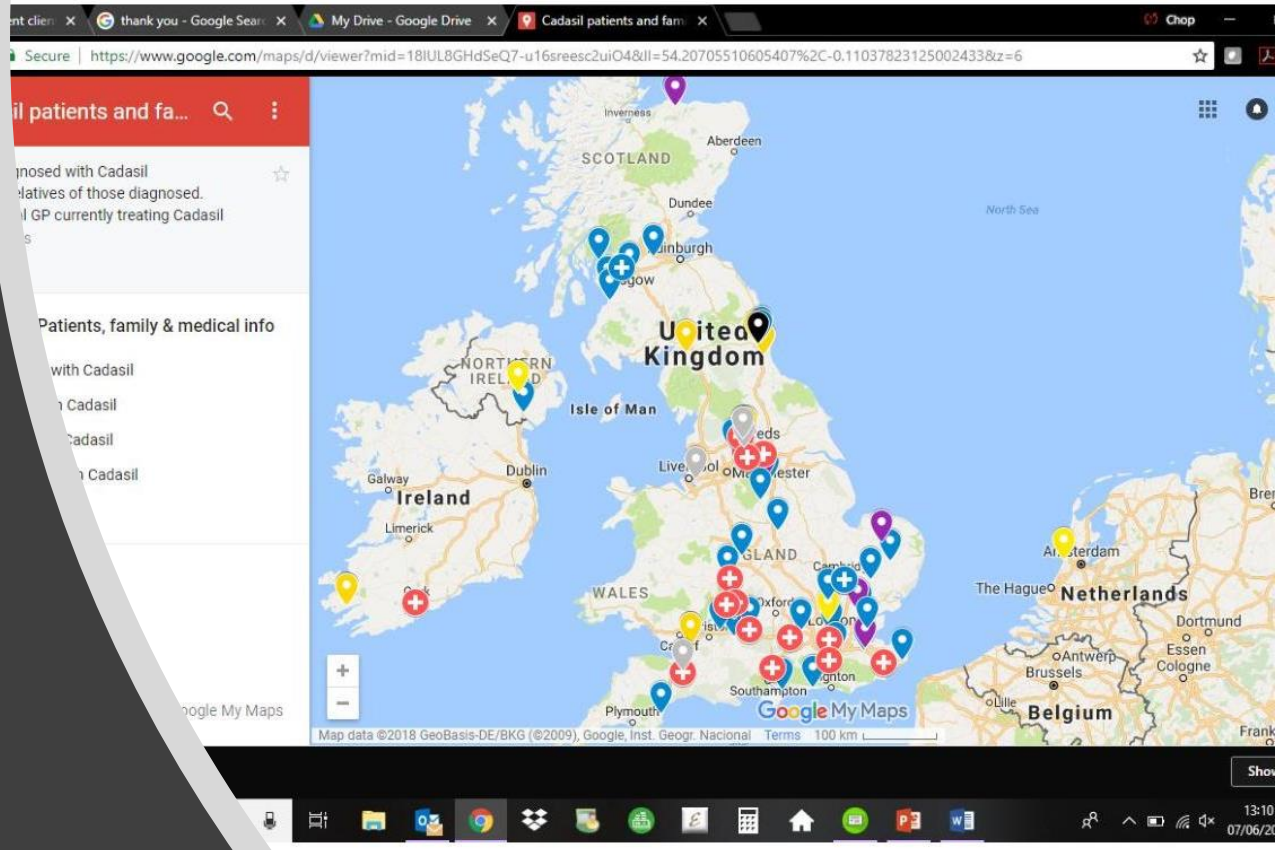
Cadasil Support UK – Facebook group

- On Facebook there is a closed group called CADASIL Support UK. (A closed group means people can search for the group, but they can't see the posts unless they are approved)
- There are currently just over 450 members.
- People are introduced by the admin when they are approved and can speak freely in there knowing everyone in there is dealing with similar issues.
- It is friendly and approachable and many people ask questions
- It does come to a bit of a stand still if things are needed or ideas but we are sure after today, it will start moving ☺
- If you don't have Facebook but do want to join you can contact me or Karen and we will help set you up an email address (if you don't have one) just so you can join the group and interact with other people



Ongoing projects

- We have produced an interactive map (which you will find on the Facebook group) which shows
  - Cadasil patients
  - Cadasil families
  - GPs aware of cadasil
  - Neurologists aware of cadasil
  - Professors involved with research
- We still need information from people with regards to their doctors/neurologists. Without this information, we can't grow and make people aware.



CADASIL Support UK – Social Media

- There are other ways to contact us – If you want to get in touch with someone in your area, or find out if there is someone in your area with CADASIL, you can
- Phone – 01422 613471
- Email – cadasiluk@yahoo.com
- Tweet - @cadasilsupport1
- Access the website – www.cadasilsupportuk.co.uk
- If you want to help with any aspects of the charity, please get in touch

Thank you

- To finish off I just want to thank the following people for their support, ideas and general input
- Glenn Bate
- Sophie Jones
- Irena Souroup
- Nigel Trout
- Susan Phillips
- Gill Powton
- Jessica Walsh
- Professor Markus


In loving memory of Jax Trout who sadly passed away from cancer on 7 November 2017