

If Thomas Edison could invent a light bulb, why can't somebody invent a cure for my rare cancer?

Isolated? Frightened? Confused?
Ever experienced these feelings?

- We want to find a group of voices to speak up for us on our paediatric GIST journey in the UK
- We want someone to help us with the correct treatment, someone who wants GISTs to be as well known as other cancers
- We want someone we can turn to for sound advice with our best interests at heart
- We want a central hub in the UK where a team knows exactly what PGIST is. They can feed back to local oncologists to make sure they are giving the correct care, and also liaise with the team in the US for advice and sharing of information
- We want a support network online as well as in clinics
- We want to find out what the protocol for PGIST patients in Europe are so we know we are all getting the same best treatment.

We need all this for us, our families and carers.

We need the support of:

Oncologists- the people who told you that you have cancer
Surgeons- the people who remove the ugly bits from inside you
Pathologists – the people who examine your tumors when they are taken out
Geneticists- people who check the cells that carry your body's information

We have already done some work towards meeting other PGIST sufferers:

We have made a group on Facebook called '**Teenagers With GISTs**' to introduce ourselves with other PGIST sufferers all over the world
We have got in touch and met up with other families in the UK to gain some extra support in fighting this rare cancer.

We have organised fundraising events so more research can go into finding a cure for PGISTs

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PGIST

For more information contact
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