



Office for  
**Rare  
Conditions**  
Glasgow

## Information & Resources

# Monthly Bulletin

May 2021

### Highlighted this month:

KIDS stands for Kids Independently Developing Skills and is a digital resource.

KIDS aims to help children to live meaningful, healthy, independent lives by providing information, advice, strategies and self-help support. KIDS is for young people, families and professionals. The information provided has been developed by a range of children's health professionals from Specialist Children's Services in NHS Greater Glasgow and Clyde.

**KIDS** <https://www.nhsggc.org.uk/KIDS>

**SWAN UK (syndromes without a name)** is the only dedicated support network available for families of children and young adults with undiagnosed genetic conditions in the UK. It is run by the charity Genetic Alliance UK. If you



want to become a member of **SWAN UK** but haven't got around to it yet, you can find their online membership application form [here](#).

**Carers Week (7-13 June 2021)** is an annual campaign to raise awareness of caring, highlight the challenges unpaid carers face and recognise the contribution they make.



[carersweek.org](https://carersweek.org)

This year's theme is Make Caring Visible and Valued. If you would like to get

involved, please check out the recently updated [Carers Week website](#) and [Add Your Voice](#) to their call to Make Caring Visible and Valued.



**Monday 28th June – Friday 2nd July 2021**

**Venue to Virtual : view equipment, products and services for all ages**

A **FREE** week-long virtual event featuring over 50 of the most prestigious and award-winning companies, demonstrating their equipment and highlighting their services. [Join Venue to Virtual - view equipment, products and services for all ages \(kidzexhibitions.co.uk\)](#)

**contact** *For families with disabled children*

### **New Contact Scotland Leaflet**

Looking for an overview on how Contact can help families in Scotland? Download their new Scotland leaflet

<https://contact.org.uk/wp-content/uploads/2021/05/Scotland-leaflet.pdf>

or email Lynn, By Your Side Parent Adviser, for printed copies [Lynn.shields@contact.org.uk](mailto:Lynn.shields@contact.org.uk)

## Contact workshops for parents and carers in Scotland!

All CONTACT's workshops are delivered via Zoom and are informative, relaxed and friendly. For more information or a flyer listing our workshops with links; email [donna.tomlin@contact.org.uk](mailto:donna.tomlin@contact.org.uk).

### Coming up:

**Supporting your child's sleep** - Thursday, 3 June, 10.30am-12.30pm. Register on our [Supporting your child's sleep workshop](#)

**Encouraging Positive Behaviour** - Thursday, 17 June, 10.30am-12.30pm Register on our [Positive Behaviour workshop](#)

**Preparing for adult life** - Thursday, 24 June, 10.30am-12.30pm Register on our [Preparing for Adult Life workshop](#)

## Helpline

CONTACT run a free helpline for parents and carers with a disabled child aged from birth to 25, living in any part of the UK. Your child does not need a diagnosis for you to call our helpline. For more details about the helpline services and hours, please see their [Helpline page](#).



## Take a Break Short Breaks Fund

Family Fund are pleased to announce that the Take a Break Short Breaks Fund is **open for applications** until **5.00pm on Monday 21 June 2021**.

Take a Break is Scotland's short breaks fund for carers of disabled children, young people and their families. Take a Break is funded by Scottish Government and administered by Family Fund. Take a Break grants can be used for a break away, towards leisure activities or outings; sports equipment and much, much [more](#).

Applicants will receive a letter from 9 July 2021 informing them of the outcome, they will not receive a decision before this date.

Some carers may be concerned about travelling both in the UK or overseas with the ongoing effects of Coronavirus, there are options on how you can use this grant. Carers have 12 months to use the grant so can wait until they feel more at ease with taking a break away. Or they can use the grant for a range of other items that help support a break at home or out and about, such as bikes, sports equipment, outdoor play equipment or home entertainment, they just need to tell us what they use the grant for.

Applications can be made [online](#) or an [application form can be downloaded](#) and return to us. We encourage applications to be submitted as soon as possible and a text message will be sent to the applicant to confirm we have received it. As funding is limited, priority will be given to carers who have not received a grant before, and those who missed out last year. For more information you can visit the [website](#) or follow Take a Break on [Facebook](#).

### It's OK to Ask

A new NHS Scotland campaign has been launched to encourage people to ask questions when they attend healthcare appointments. Suggested questions that someone might ask during a healthcare appointment may include:

- What are the benefits of my treatment?
- What are the risks of my treatment?
- Any alternative treatments I can try?
- What if I do nothing?

More information including a communications toolkit with social media posts and images so you can support the campaign, can be found on [It's OK to Ask | NHS inform](#)