



Office for
**Rare
Conditions**
Glasgow

Information & Resources Bulletin July 2021

Highlighted in this bulletin

How will you say #HelloYellow this year?

Saying #HelloYellow this World Mental Health Day is a little thing we can do to make a BIG difference to young people's mental health. Join thousands of schools, offices, and communities across the UK on Friday 8 October by wearing yellow and helping raise vital funds. Together we can show young people they are not alone with their mental health.

<https://youngminds.org.uk/contact-us/sign-up-for-helloyellow/>

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](#).



Sibs

For brothers and sisters
of disabled children and adults

Sibs exists to support people who grow up with or have grown up with a disabled brother or sister. It is the only UK charity representing the needs of over half a million young siblings and over one and a half million adult siblings. Sibs has a range of resources to support siblings of all ages. For more information check out their [webpage \(https://www.sibs.org.uk/\)](https://www.sibs.org.uk/)



Rare Resources: Scotland is a guide produced by Genetic Alliance UK for families in Scotland who have recently received a diagnosis of a genetic or rare condition, who are on the journey to a diagnosis or families who have been told their child's condition is so rare they might not get a diagnosis.

The Toolkit contains a wide range of general information on genetic, rare and undiagnosed conditions as well as information on how to access reliable information, care and support in Scotland.

<https://geneticalliance.org.uk/information/living-with-a-genetic-condition/rare-resources/>



ALLIANCE

The Discover Digital team have created a guide to help people understand and navigate digital health, care and wellbeing tools and services. Simply signposting to digital tools, however helpful they might be, is not enough. People also need support to develop the skills, knowledge and confidence that they need to be able to use these tools.

This document is the Health and Social Care Alliance Scotland's first attempt at building a resource to support with this task. It is very much a first draft and they are looking for as much feedback as possible.

<https://www.alliance-scotland.org.uk/blog/resources/discover-digital-guide/>

Counting the Costs 2021 – Take our family finances survey

#CountingTheCosts contact

How has the pandemic affected your family's finances?

Help us campaign for better financial support for families with disabled children. Take our survey for a chance to win a £100 voucher!

[contact.org.uk/campaigning](https://www.contact.org.uk/campaigning)

SURVEY CLOSING ON 7 JULY AT 9AM

How has the pandemic affected your family's finances? Tell Contact about it for a chance to win a £100 voucher! <https://www.surveymonkey.co.uk/r/CountingtheCosts>

This year, Contact's landmark CountingTheCosts survey will provide a unique snapshot of how Covid-19 has affected the incomes of families with disabled children in the UK. This includes:

- ◆ The impact of shielding and furlough
- ◆ Extra caring duties and working hours
- ◆ Impact on benefits like DLA and Universal Credit
- ◆ Going without (or accruing debt)
- ◆ Concerns about the future

Your answers will help Contact build a stronger case with government for better financial support for families. The survey is open until 7 July and takes around 25 minutes to complete. As a thank-you for your time, you will be entered into a draw to win one of three £100 vouchers.

It's open to all UK families of children with any disability or additional need. Please share it with your family, friends and wider networks.



Family Fund

Helping disabled children

Family Fund

SUMMER SCHOOL

Sign up now!

iPad Summer School.

Unlock your child's creativity and learn more about what their iPad can do

through free virtual sessions. To find out more go to

<https://www.familyfund.org.uk/ipad-summer-school-2021>



When it comes to your healthcare,

it's OK to ask questions...

Any alternative treatments I can try?



Find out more >

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](#)