

Remember, if you care for a disabled child and need advice, support or information about benefits or any other aspect of raising a disabled child you can call Contact's free helpline on **0808 808 3555** to talk to one of our parent advisers.

### Lifeline appeal update

Did you know our **Family Finances Helpline** is the only specialist independent helpline of its kind? This service is currently funded by the Big Lottery but that funding comes to an end in June. For every £10 donated towards this service, we secure an extra £130 in the pockets of families through our expert advice on the benefits system. Last year we helped secure an additional £2 million for families with disabled children. Thanks to you we are delighted to report that our appeal has so far raised £2150 and donations keep coming in. Please help us keep our family finances helpline open. With your support, we'll be at the other end of the line for families for a long time to come.

### Universal Credit cuts High Court challenge by family with disabled child

A family whose income dropped when they were forced onto Universal Credit took their case to the High Court on 23 January. The charity Child Poverty Action Group has taken a case to court on behalf of a single parent with a 12 year old disabled child who were told to claim Universal Credit when they were waiting for the child's DLA claim to be renewed. This left them £140 a month worse off. This is the first time that the courts will have looked at how Universal Credit impacts on disabled children and we are watching with interest.

### How I won my son's DLA

Julia tells us about meeting Derek from our family finances helpline after he helped her win an appeal for the mobility element of Disability Living Allowance for her son. "Derek's invaluable and knowledgeable advice ensured that the appeal was successful and my son got the financial support he deserves."

### Families affected by Universal Credit – we need you!

Contact is continuing to campaign against the cuts to disability payments under Universal Credit which will affect 100,000 disabled children and their families. A big part of this is gathering stories from affected families. We want to show all the different ways families are ending up on Universal Credit and what impact it has had. We'd love to hear from you. Get in touch by email: [press@contact.org.uk](mailto:press@contact.org.uk) or text **07599 930 090** with your name and a good time to call.

### Larger families lose exemption from Universal Credit

Last week (1st February) the rule that exempted larger families (3 or more children) from having to claim Universal Credit was scrapped. If you try and make a new claim for a means tested benefit like Income Support or Housing Benefit or a new claim

for tax credits, you will now be told that you need to consider claiming Universal Credit instead, regardless of the fact that you have more than two children.

### Some disabled adults are now exempt from claiming Universal Credit

During January the government introduced new rules to exempt some disabled adults from Universal Credit. If a disabled person has qualified for a payment known as the severe disability premium in the past month, they are exempt from claiming Universal Credit and can still make new claims for the old benefits and tax credits that Universal Credit is replacing. Contact our free Helpline if you are a disabled parent and you are not sure whether you have been getting the severe disability premium or not.

### Mixed age' couples and Universal Credit

Currently, if a couple includes one person of pension credit age and a younger partner they can claim Pension Credit. However, from 15th May 2019 mixed age couples who are making a new claim will need to claim Universal Credit instead. Payments are significantly lower under Universal Credit than under Pension Credit, so it's really important that any mixed age couples on a low income get urgent advice about whether they can claim Pension Credit before 15th May.

### Other changes to Universal Credit

The government has announced plans to make a number of other changes to Universal Credit. This includes delaying the start of process of 'managed migration' of existing benefit claimants onto Universal Credit. Find out more here. Remember if you are worried about your family's financial future you can give our Freephone helpline a call to find out how we can help reduce some of your money worries. We have specialist benefits advisers, funded by the Big Lottery to provide detailed advice on any aspect of the benefits and tax credits system.

### Parent guides

We have an updated guide to Personal independence Payment which you can download for free from our website. We also have a financial checklist for parents Money Matters and our guide to claiming Disability Living Allowance for a child.

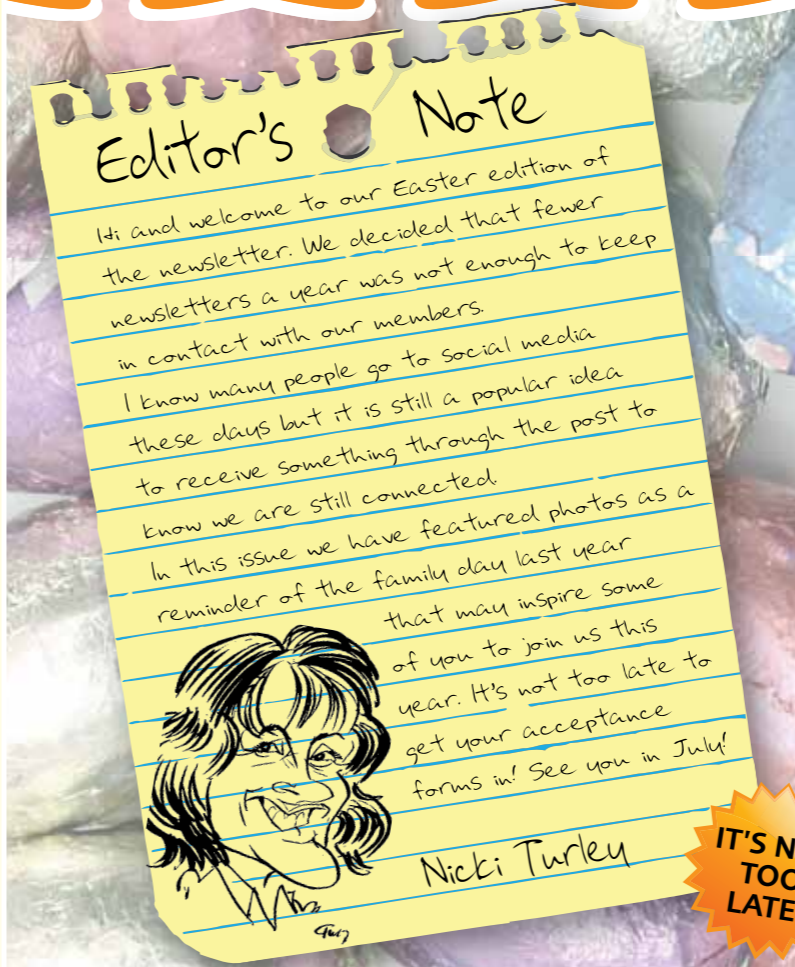
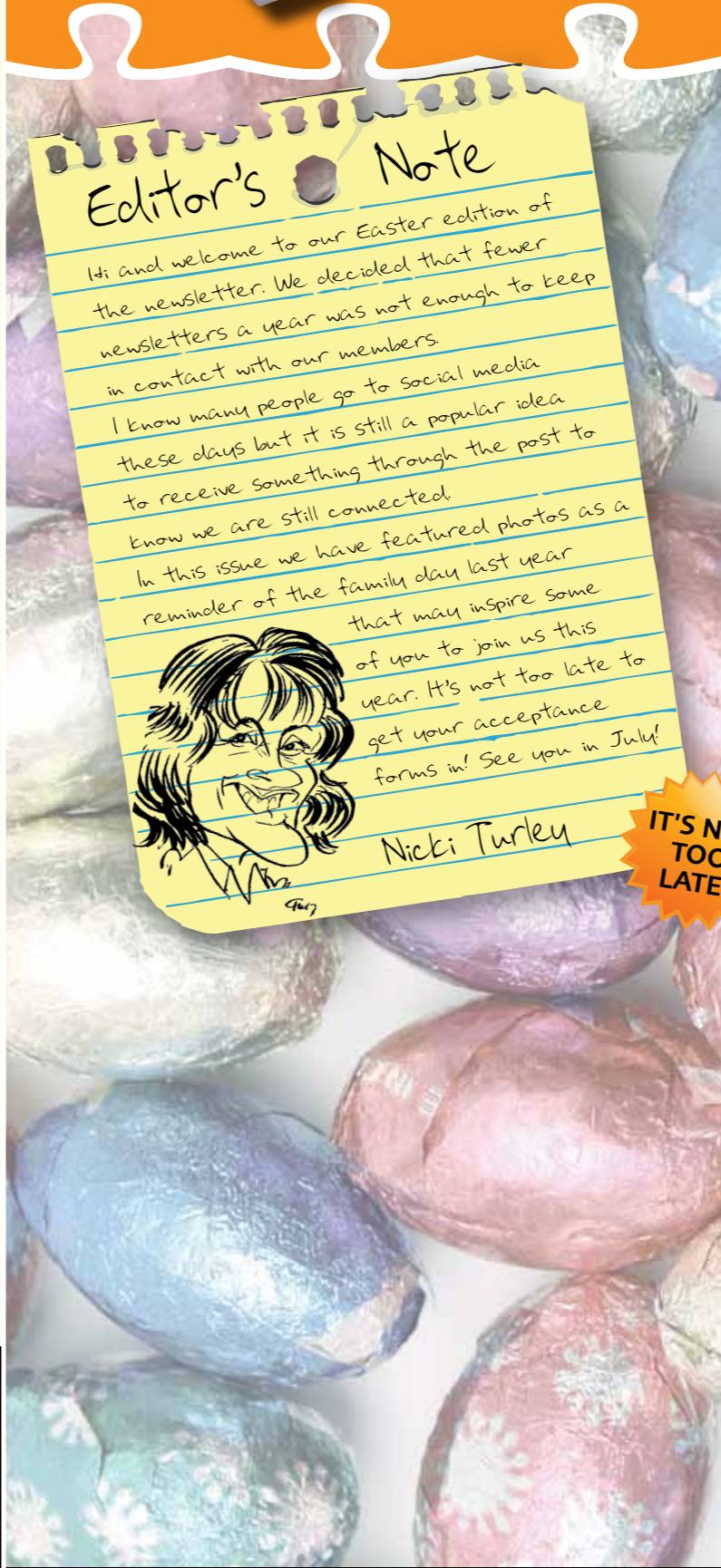
### Keep up to date with the latest news and information from Contact

Our **What's New Benefits Special** is just one of a whole range of newsletters we offer so you are kept up-to-date with all the latest disability news, updates about Contact's work and activities, and opportunities for you to get involved in what we do.

### Got your copy of the Helpful Guide for Families with Disabled Children yet?

We've published **The Helpful Guide for Families with Disabled Children**, a comprehensive companion for all parents about the many ways we can support you. If you'd like a copy of our helpful guide, simply complete our online application form. We'll send you a copy within a couple of weeks.

Article provided by Contact



**Editor's Note**

Hi and welcome to our Easter edition of the newsletter. We decided that fewer newsletters a year was not enough to keep in contact with our members. I know many people go to social media these days but it is still a popular idea to receive something through the post to know we are still connected. In this issue we have featured photos as a reminder of the family day last year that may inspire some of you to join us this year. It's not too late to get your acceptance forms in! See you in July!



Nicki Turley



## In this issue

<b>From the Chair</b>	<b>2</b>
<b>Family Day</b>	<b>2/3</b>
<b>Money Matters</b>	<b>4</b>

Don't forget to send your articles or any news that you would like to see in future issues to: [secretary@wdssg.org.uk](mailto:secretary@wdssg.org.uk)

Please let me know if you have anything that you would like to share with other members.

## From the Chair

Welcome to another edition of the newsletter. I am glad to see that our numbers are doing well with some new faces in the WDS family.

Although charities are struggling with finances being stretched, we are still able to offer support to families and those affected with WDS. This engagement is important to us and we are always open to new ideas.

I am aware that many of our members who joined as children are now adults. It is important for them to have a safe place to share their experiences and gain support from each other. Mental health has been a growing cause for concern in the media and social networks are not doing enough to help young adults. Having said that, with many people with WDS



having communication difficulties, it is even more important that we make sure that we can do the utmost to help each other and not to become isolated.

We have tried different methods before, using Makaton symbols to tell member stories, but we are open to any suggestions.

Lastly, I have been in talks with the committee in raising awareness of the syndrome within the medical profession, so hopefully we will be able to bring you some news on this in the near future. I will look forward to seeing some of you soon at the WDS family day.

Mark Mayer

## Tax

By the time you receive this newsletter we will already be in the new tax year 2019-20 so you will be getting tax forms to complete for the year 2018-19. This is just a reminder that if you are in the higher rate tax band, I believe you can claim any money you gave to UK charities on your tax form.

Please note that I am not a tax advisor, so if you need tax advice please seek it from someone that is qualified to do so.

**Did you know if you do not earn enough to use all of your personal tax allowance you may be able to give some of it to your partner? This also works the other way around.**

[www.gov.uk/marriage-allowance](http://www.gov.uk/marriage-allowance)

John Butt

## Membership Database Verification

Over the last month you should have heard from us as we have been checking that we have all the correct contact information for you. Thank you to all who have replied.

If you have not yet replied please can you do so as under the Data Protection Laws we have to ensure that the data we hold is accurate or delete you from our membership list?

In addition we are in the process of trying to find out where all our children have been diagnosed, from the feedback that we have received so far most of our families are still being diagnosed in London but it seems that there are a few other locations that are diagnosing children with WDS, two others being Birmingham and Oxford.

We are also undertaking a piece of work to get more awareness of WDS so we will update you in the coming months.

Vanessa Butt (National Contact)

## Family Case Studies

All the information on the original study by Dr Worster-Drought in the 1950's have been lost so please think about writing a piece for the group or writing a Family Case History that we can publish on our web site.

[www.wdssg.org/family-case-history](http://www.wdssg.org/family-case-history) for guidance.



*This year's Family Day is on Sunday 14th July 2019*

We are returning to our popular venue again for our annual family day and AGM this year.

To find out more about the facilities then please look at:

[www.tvap.co.uk](http://www.tvap.co.uk)

Thames Valley Adventure Playground, Bath Road, Taplow, Nr. Maidenhead, Berkshire, SL6 0PR

Or if you require any other information please contact Vanessa [national.contact@wdssg.org.uk](mailto:national.contact@wdssg.org.uk)

You should have received your invitations for the Family Day in the post by now and your acceptance forms will need to be returned to Vanessa (National Contact) by **30th April**.

As in previous years the AGM will be held on the Family Day. This year however, as a change to our usual schedule, the AGM will be held at noon just before we take a break for lunch.

The Agenda for the day will be:

10 - 10.30am	Registration and refreshments
10.30 - 11.15am	The return of Paul Megram as magician 'Colonel Mustard'
11.15 - 11.30am	Tea break
11.30 - 12.00	Time to enjoy the facilities and meet and chat with other families and members
12.00 - 12.15pm	AGM
12.15 - 1.30pm	Lunch
1.30pm - end	Informal afternoon to meet and mingle

(all times are subject to change)

There will be tea and coffee making facilities ONLY throughout the day. Please feel free to bring your own cups if you do not wish to use plastic ones. **PLEASE BRING A PACKED LUNCH.**

## COLONEL CUSTARD RETURNS

Paul Megram (Colonel Custard) has been entertaining children for over 20 years with his unique blend of fun-filled magical mayhem. His award-winning children's shows have taken him around the world delighting audiences both young & old with his crazy antics.



Offering a whole host of exciting activities catering for all ages from tots to teens.

VOTED UK CHILDREN'S ENTERTAINER OF THE YEAR IN 2014 & 2015

A MEMBER OF THE MAGIC CIRCLE  
BRITISH MAGICAL CHAMPION  
CRB & DBS CHECKED  
GREAT VALUE FOR MONEY

**BACK THIS YEAR!**

